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Development of a Pain Management Life History Calendar

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Development of a Pain Management Life History Calendar

Jennifer Margaret Hehl, PhD

University of Connecticut, 2018

The purpose of this study was to develop and test a computerized pain management life history calendar (PMLHC) for use with older adults with osteoarthritis. A two-phase, descriptive research design was used to test the instrument for clinical and research applications. In Phase 1 focus groups, providers ($N = 10$) shared their thoughts of a mockup PMLHC output. During Phase 2, community dwelling older adults ($N = 24$) filled out a PMLHC and were interviewed for opinions and pain management history. An iterative process was used to refine the instrument using feedback from the participants and researcher observations. Test-edit-retest cycles continued until saturation was reached on instrument development ideas.

Content analysis on transcripts of audio recordings from focus group discussions and individual interviews used *a priori* coding categories of positive comments, negative comments, supportive and non-supportive comments of feasibility and acceptability, and missing items and ideas for improvement. From the providers' and patients' transcripts, data were coded and clustered into the categories of PMLHC affirmations, areas of concern, and missing features and ideas for PMLHC development. A descriptive examination was completed about older adults' PMLHCs. Examples of PMLHC data included when treatments began, duration of treatments, timing of changes, medications, complementary/alternative treatments, and pain intensity and interference with function outcomes for each treatment. Content accuracy was examined for the final version with a subset of 12 older adults.

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Providers expressed support for a future version integrated with electronic health records, although results indicated the current version was not acceptable. Due to errors noted in multiple timelines, the self-administered PMLHC for older adults was deemed not yet feasible for use. In addition, older adults reported that filling out the PMLHC was a self-reflective activity that helped them think more about their pain self-management efforts. Future work should explore the self-reflection potential of the PMLHC compared with pain management outcomes. With further development, the PMLHC has the potential to enhance communication about past pain management strategies and assist to identify more tailored pain treatment regimens.

Development of a Pain Management Life History Calendar

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A Dissertation

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at the

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2018

APPROVAL PAGE

Doctor of Philosophy Dissertation

Development of a Pain Management Life History Calendar

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Table of Contents

List of Tables	ix
List of Figures	x
Chapter 1: Introduction	1
Significance of the Problem.....	1
Pain: As a public health issue	1
Older adults and pain communication	2
Life history calendars.....	3
Conceptual Underpinning	4
Purpose.....	7
Significance of Study/Gap in Literature	8
Summary	8
Chapter 2: Review of Literature	10
Trialing to Pain Control, a Grounded Theory.....	10
Communication Accommodation Theory.....	13
Memory Structure: A Precursor to Life History Calendar Methodology	17
Background Information on Life History Calendar Research	18
Overview of Osteoarthritis Pain Management in Older Adults.....	24
Patients' Use of Computerized Medical History Collection Instruments.....	28
Older Adults' Feasibility of Computer Use	32
Summary	34
Chapter 3: Design and Methodology	36
Study Design Overview	36
Focus Group Methodology	38
Planning group composition and size	39

Developing a questioning route	40
Numbers of participants	41
Moderator skills	41
Content Analysis Methodology	41
Phase 1: Feasibility and Acceptability of Using the Pain Management Life History Calendar: The Provider Perspective.....	44
Design	44
Sample and setting	44
Instruments.....	45
Procedure	45
Data analysis	47
Phase 2: Feasibility of Using the Pain Management Life History Calendar: The Patient Perspective.	48
Design	48
Sample and setting	49
Instruments.....	50
Procedures.....	53
Data analysis	57
Rigor	59
Summary	59
Chapter 4: Results	61
Phase 1: Feasibility and Acceptability of Using the Pain Management Life History Calendar: The Provider Perspective.....	61
Provider characteristics	61
Phase 1 content analysis results	62
PMLHC affirmations	63

Areas of concern	65
Missing features and ideas for PMLHC development.	67
Phase 2: Feasibility of Using the Pain Management Life History Calendar: The Patient Perspective.	68
Participant characteristics	69
Phase 2, Part 1: What did participants think of the PMLHC?	70
Phase 2, Part 2: Pilot test for accuracy of PMLHCs	74
Development and accuracy of the PMLHC.	77
Phase 2, Part 3: Contents of pilot PMLHCs	78
Summary	80
Chapter 5: Discussion	82
Overview and Purpose of the Study.....	82
Findings for the Research Questions	82
Challenges for Future Versions of the PMLHC	84
Pain self-management content generated from the PMLHC	94
Limitations	96
Implications for Future Research.....	98
Conclusions.....	100
References	104
Appendix A: Theory of Trialing to Pain Control.....	137
Appendix B: Provider Participant Demographic Form	138
Appendix C: Phase 1 Fictitious Patient PMLHC Printout.....	139
Appendix D: Provider Focus Group Discussion Guide.....	141
Appendix E: Patient Participant Demographic Form	143
Appendix F: Screen Shots of Final Version of Computerized PMLHC.....	144
Appendix G: Patient Focus Group Interview Guide.....	156

Appendix H: Older Adult Interview Guide	157
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List of Tables

Table 1. Phase 1 Coded Data for Positive Features	125
Table 2. Phase 1 Coded Data for Support of Feasibility.....	126
Table 3. Phase 1 PMLHC Affirmations Cluster	127
Table 4. Phase 1 Areas of Concern Cluster	128
Table 5. Phase 1 Missing Features and Ideas for PMLHC Development	129
Table 6. Phase 2 Older Adults' PMLHC Affirmations Cluster	130
Table 7. Phase 2 Older Adults' Areas of Concern Cluster	131
Table 8. Phase 2 Older Adults' Missing Features and Ideas for PMLHC Development	132
Table 9. Phase 2 Participants Cross Referenced to PMLHC Versions and Edits.....	133
Table 10. Phase 2 Participants' PMLHC's Rounds of Treatments and Outcomes.....	134
Table 11. Phase 2 Participants Arthritis Sites and Treatments	135

List of Figures

Figure 1. Phase 2 participant inclusion.	136
Figure A1. Theory of trialing to pain control.	137

Chapter 1: Introduction

Whyte (1952) stated, “The great enemy of communication, we find, is the illusion of it” (p. 154). Every patient-provider encounter requires the need for good communication, which is critical for older adults with osteoarthritis (OA) pain. This population has a small number of pain treatment options. Due to this limitation, primary care providers must frequently adjust pain treatment regimens for older adults with OA pain to make the most of the few treatments available. Too many older adults with chronic pain from OA do not achieve optimum outcomes for pain relief or functionality loss due to pain despite multiple visits to their providers. Traditionally, one of nursing’s roles has involved helping people adapt to, manage, and cope with the effects of their illnesses and medical conditions through nursing interventions, such as support with activities of daily living and patient teaching. This research project was conceived to teach patients to communicate with providers effectively by advocating for their pain management needs.

Significance of the Problem

Pain: As a public health issue. The number of adults in the United States with arthritis is estimated at 47.5 million, with as many as 47.1% of those adults living with persistent pain from their arthritis (Kennedy, Roll, Schraudner, Murphy, & McPherson, 2014). The discomfort of painful joints is not just an unpleasant phenomenon that people live with; arthritic pain can also become a source of disability and severely limit a persons’ activities (MacDonald, Sanmartin, Langlois, & Marshall, 2014; Peat, Wilkie, & Croft, 2009). Studies have shown that older adults in pain are vulnerable to social isolation due to a decreased capacity to participate, health related quality of life, and overall life satisfaction, as well as the development of depression (Simsek et al., 2010; Tse, Wan, & Wong, 2013).

In addition to human suffering, researchers have acknowledged that pain patients can contribute to added medical expenses and lost work days, estimated at costing the United States up to \$293 billion per year (Gaskin & Richard, 2012). According to Nahin (2015), the number of U.S. adults experiencing pain was estimated as 126 million people, with 63 million describing their pain as chronic or severe. The U.S. Institute of Medicine (IOM, 2011) reported that 116 million adults suffered from chronic pain of all types, thereby identifying chronic pain as a major public health issue. While the exact number of people with chronic pain varied by report, a large number of people were affected. The IOM (2011) suggested that a health care cultural transformation was needed in the United States to improve assessment, prevention, treatment, and knowledge of pain issues. The IOM covered many suggestions that included ways to organize national efforts, areas that needed additional focus and research, and the need for robust implementation studies. The IOM shared that one part of the puzzle of assessment and treatment of chronic pain involved researchers finding ways to improve provider-patient communications.

Older adults and pain communication. Many older adults living with OA pain fail to achieve adequate pain relief despite treatment options and visits to their providers for help (MacDonald et al., 2014; McDonald & Molloy, 2010). Researchers have suggested that barriers to pain relief exist on both sides of the provider and patient relationship. Barriers include mistrust of medications (fear of adverse effects and risk of addiction), poor compliance with treatment regimens, lack of provider follow up, and poor communication (Fitzcharles, Lussier, & Shir, 2010; Shields et al., 2013). Additionally, many older adults believe that pain is an inevitable part of aging, and treatments will not provide them with any meaningful benefits (Gammons & Caswell, 2014; Thielke, Sale, & Reid, 2012). Poor communication was evident when older adults sought treatment for pain control from primary care providers, and then

described leaving confused about their diagnosis, as they felt misunderstood about their pain experiences (Clarke et al., 2014).

While some providers may need to learn to manage arthritis pain effectively, researchers have suggested that patients who actively participate in decision making and ask more relevant questions experienced better pain management outcomes (Elwyn et al., 2016; K. Robinson et al., 2017). Researchers have shown that older adults with moderate levels of pain may fail to discuss pain issues with their providers (Haskard-Zolnierok, 2011; Hehl & McDonald, 2014). The present research aimed to develop a way to help older adults communicate more effectively and participate in their pain management through an electronic communication instrument that could capture patient-generated health data about their history of pain treatments.

Life history calendars. One of the challenges in recording historical information involved how much and how well people remembered. This study utilized an adapted version of the life history calendar (LHC) methodology to help older adults have greater recall of their osteoarthritis pain management histories. Researchers have used the LHC method as a research tool to collect retrospective data (Bay-Cheng, 2017; Belli & Callegaro, 2009; McNeely et al., 2015; Ricks & Harrison, 2011). Through guided recollection of the timelines for specific events or topics, people using the LHC could remember details that occurred over long periods (Freedman, Thornton, Camburn, Alwin, & Young-Demarco, 1988; Martyn & Belli, 2002). Martyn and Belli (2002) suggested that LHCs could be adapted to nursing research to collect information about topics, such as disease management and pain symptoms, health promotion and risk behaviors, and adherence to treatment regimens. McDonald and Barri (2015) used a Pain Management LHC (PMLHC) with older adults in face-to-face interviews about their OA pain management trajectory to test the PMLHC method as a pain management instrument. The

PMLHC interviews produced timelines of information about pain treatments that a provider could use as a basis for intervention (McDonald & Barri, 2015). Using the PMLHC as a conversation starter, a provider might identify previously failed treatment regimens that could be improved through recommendations of different doses and frequencies or longer trials.

Conceptual Underpinning

The two theories that guided this project included the trialing to pain control grounded theory and communication accommodation theory. The importance of improving pain management information communication between providers and patients was paramount in the grounded theory of trialing to pain control (McDonald, 2014). With an understanding of the issues and social processes that contributed to the problem of inadequate pain relief of chronic pain in adults, McDonald's (2014) grounded theory indicated a four-phase approach for patients and providers. In the first phase—finding the right provider to treat the pain—patients describe the “right provider” as someone who got to know them, their pain, and how they responded to treatments. Patients need to persevere until they find the provider with whom they can productively and cooperatively communicate. In the second phase—initiating the pain treatment trial—patients and providers agree to a tentative plan, with both having input about possible issues and an understanding that this is the first step in a multistep process. If patients have struggled with chronic pain, they may feel hopeless and like they are out of options for pain control, but the right provider can make suggested adjustments, even to treatments that have been tried in the past. In the third phase—adjusting the pain treatments—the provider and patient work together to understand the patient's response to the treatment plan, and they cooperatively decide on pain management changes. Communication must remain open throughout the phases to allow adjustments to the treatment plan. In the fourth phase—continuing to adjust treatments

as patients take control over their plan—patients become empowered to take control of their pain and can also regain energy to engage in their lives. In this phase, patients and providers remain in communication as needed to adjust the treatment plan, but the needed changes should be less frequent. Patients may still have some remaining pain but feel more in control of the experience and know that they have a strong ally with the “right” provider (McDonald, 2014).

Trialing to pain control theory, as the main theory guiding the present research, indicates interventions that improve communication between patients and providers may improve pain control outcomes for patients with chronic pain (McDonald, 2014). For the second phase of trialing to pain control, a thorough understanding of the patient’s pain management history could help providers generate focused follow-up questions and suggest different combinations of treatments, new strengths of medications, or untried treatments. The large number of affected people and the continued economic, quality of life, and social toll of poorly treated chronic pain warranted this communication-based, teamwork approach to pain management.

Underlying the four phases of trialing to pain control theory was the need for effective communication between provider and patient. Researchers have developed the communication accommodation theory (CAT) over 40 years to help explain the complexity of human interactions, including how and why people communicate (Giles & Ogay, 2006). The theory posits that humans adapt their speech patterns, word choices, speed of discourse, and their accents based on perceptions of the person they are speaking with; moreover, these communication choices carry social implications that people have learned to negotiate with varying degrees of success. The CAT describes ways in which people can choose either accommodation or non-accommodation in any given conversation or social situation. By utilizing different communication strategies, people can attempt to be like others, make others

more comfortable, and seek to be understood, or they can choose the opposite behaviors (Giles, 2016). For the medical setting, CAT offered insights into possible interventions to help improve communication between providers and patients. Baker and Watson (2015) suggested that examining patient-provider communication using CAT might allow researchers to understand why some patients might choose to not fully communicate. Farzadnia and Giles (2015) suggested that CAT could be used as a framework to suggest interventions to improve provider-patient communications.

In a descriptive study examining ways in which providers and patients discussed pain management issues during office visits, Hehl and McDonald (2014) conducted a secondary analysis of audiotaped primary care office visits of 22 community dwelling adults. The authors sought to explore the pain topic communications between older adults and providers using the following six *a priori* communication strategies adapted from CAT: (a) patient selecting the pain topic, (b) patient taking a turn, (c) patient maintaining focus on the pain topic, (d) provider using an open-ended question without social desirability to start the pain discussion, (e) provider encouraging the patient to take a turn by asking open-ended questions, and (f) provider interruptions. Hehl and McDonald observed that older adults had trouble maintaining focus on the pain topic during these consultations. By applying CAT as a lens with which to view provider-patient interactions, researchers observed areas of communication break downs. From this observation, a need existed to explore methods to improve older adults' communication of pain management information.

The CAT showed potential communication issues, including perception of provider power, language barrier of medical terminology, and the social desire for approval and acceptance of patients (Wald et al., 2010). Having patients record relevant historical information

before their time-limited office visits might overcome the problem of patients giving incomplete information during office visits. Patient-generated health data might help patients be more engaged in their health care and could improve pain management outcomes (Wald et al., 2010). A succinctly recorded history could provide a useful starting place for patients and providers to begin the work of trialing to pain control.

Purpose

The purpose of this study was to develop and test a computerized PMLHC. Initially, the computerized PMLHC was tested for feasibility in the clinical setting with a possibility of also testing it as an online research data gathering instrument. Utilizing a three phase approach, this project examined the following initial research questions:

1. Is the output from the computerized PMLHC a feasible and acceptable pain management instrument for use by primary care providers?
2. Is the computerized PMLHC a usable instrument for older adults?
3. Is the PMLHC a feasible pain management instrument in the clinical setting?
4. What pain management communication occurs between provider and patient when they use the PMLHC during an office visit?

If Phase 1 data showed the instrument as unacceptable to providers in its current format, the researcher would develop and test the instrument as a research instrument, using the following research questions for amended Phases 2 and 3:

1. Is the computerized PMLHC a useable instrument for older adults and does the computerized PMLHC collect accurate pain management histories as compared to interview data?
2. Is the computerized PMLHC a feasible pain management research instrument?

Significance of Study/Gap in Literature

The significance of this study involved developing and testing an online instrument for patient-generated data about their OA pain management histories. Significant work has occurred on patient pain assessment instruments for both paper and computerized formats (e.g., the McGill Pain Questionnaire, the Brief Pain Inventory—Short Form, etc.). These instruments have recorded various levels of detailed information about the current experience of pain, such as the type of pain felt; the intensity of the pain; the location of pain; and ways in which pain influences the patient's moods, relationships, and abilities to work (Cleeland, 2009; Younger, McCue, & Mackey, 2009). No other research was found about adapting pain management histories into an online patient-generated health data format. Trialing to pain control theory indicated that improving communication between provider and patient could help with pain management outcomes (McDonald, 2014). The concept for the computerized PMLHC derived from examining research on the social interactions occurring between older adults and providers through the lens of the CAT. This research could help researchers understand how patients have treated their OA over time, as well as the results they experienced from various treatments. Patterns in their pain management histories could indicate areas for future research and interventions to help improve outcomes for people with OA pain.

Summary

This chapter included a description of the need for interventions that could help patients communicate more effectively with their providers to achieve better pain outcomes. The concept of this study involved creating an online instrument to facilitate older adults in communicating their OA pain management histories that would be useful in clinical and/or research settings. By combining elements from provider-patient communication research, the CAT, and the trialing to pain control theory, the computerized Pain Management Life History Calendar (PMLHC)

instrument was developed. By helping older adults communicate their comprehensive pain management histories, the PMLHC was considered a first step in improving pain management outcomes for older adults with OA pain.

Chapter 2 includes an in-depth look at the related research and literature that informed this study. Chapter 3 contains descriptions of the methodology of the multiphase study, as well as the test feasibility and acceptability of the instrument in both the clinical and research settings. Chapter 4 includes a description and analysis of the data from each of the phases. Finally, Chapter 5 entails a discussion of the overall findings and implications of the study.

Chapter 2: Review of Literature

This chapter reviews the research and literature that informed each aspect of this study. The review begins with the trialing to pain control and communication accommodation theories. The review shows ways in which these theories shaped the creation of the computerized PMLHC. The LHC methodology, development, and testing will be discussed to explore the rationale for the methodology chosen to guide the creation of the computerized PMLHC. Background information will be covered about Dr. Neisser's (1986, 1997) work on autobiographical memory structure and how this tied into the development of the LHC methodology. In addition, the review explores issues in chronic pain management for older adults with OA. Finally, this chapter explores patient-generated health data, using computerized medical history collection instruments, and older adults' feasibility of computer use.

Trialing to Pain Control, a Grounded Theory

The concept for the present study was formed by examining aspects of the trialing to pain control theory, which McDonald (2014) developed as a general theory of pain management. By applying a theory of general pain management, providers and researchers could organize and focus their approaches to help patients with chronic pain. McDonald used the grounded theory methodology of Glaser (1978) and Glaser and Strauss (1967). McDonald (2014) identified the basic problem with pain management facing providers and patients as the perception of running out of options for treatments.

McDonald (2014) defined the social psychological process for overcoming the basic problem as trialing to pain control. In many medical settings, trialing is a process that involves trying a treatment regimen, assessing the outcomes, and then changing or keeping the treatment to personalize outcomes for a particular patient (Kalso, Edwards, Moore, & McQuay, 2004; Mian & Scott, 2015). Trialing can become a powerful tool for providers and patients who are

experiencing the hopelessness of feeling like they are running out of options to treat chronic pain. Trialing to pain control theory defines specific elements that contribute to successful trialing for patients with chronic pain (see Figure A1 for an illustration of the trialing to pain control theory).

McDonald (2014) identified four phases of trialing to pain control that providers and patients utilized for pain management. The first phase involves finding the right provider. The right provider sets a tone of mutual respect, is willing to listen to the patient, and works to achieve consensus with the patient regarding the treatment plan. The right provider must approach pain management with a positive attitude and be sensitive to patient concerns about prescribed treatments (worries about side effects, cost of therapies, etc.). The right provider can partner with the patient to collaborate on treatment plans, overcome patient doubts, and communicate frequently to adjust treatments based on patient and symptom responses.

The second phase in trialing to pain control involves initiating the pain treatment trial (McDonald, 2014). In this phase, the provider and patient have agreed on a course of action and both are cooperatively engaged to find an effective course of treatment. Both parties need to understand the premise of a trial and be willing to communicate openly about problems that may arise with the treatment. Patients and providers must be willing to commit to the trialing process, even as they recognize that the journey may not be short or simple. Remaining open-minded about treatment choices and being willing to revisit previously discarded treatment options is another important component of initiating the pain treatment trial phase (McDonald, 2014).

The third phase in trialing to pain control theory involves adjusting the pain treatments (McDonald, 2014). Providers and patients need to communicate about outcomes and effectiveness of the plan, and then adjust treatments based on the patient's response. Providers

need to reinforce with patients the importance of communicating any side effects or problems that arise from prescribed treatments (McDonald, 2014). Patients must have permission to communicate with a provider between scheduled appointments, which is a critical component of adjusting the pain treatment phase. When patients do not communicate their concerns, they may change their treatment plan by stopping a medication or therapy, thereby resulting in continued pain (McDonald, 2014). Providers are challenged to maintain a respectful tone when discussing the patient's choice to discontinue a treatment without first communicating the problems. For this phase to work, patients must be willing to remain engaged in their pain management and communicate with providers when problems develop with the treatments prescribed (McDonald, 2014).

The fourth phase of trialing to pain control involved continuing to adjust treatments as patients take control over their pain (McDonald, 2014). This phase is reached when patients have achieved manageable and acceptable levels of pain. Patients in this phase can re-engage in their lives, even if they have some remaining pain. They continue to follow the treatment plan and may still require adjustments to the overall pain management plan but the changes typically become less frequent. Patients who fail to reach pain control have to face living with the pain, or they may choose to start the process again and hope to find the right provider the next time (McDonald, 2014).

The theory of trialing to pain control directly contributed to the present research through the concept in Phase 3 that patients and providers needed to be willing to revisit past treatments. The PMLHC was conceived as a communication intervention that could record the pain treatments that a patient tried by aiding the recall of historical information. As a communication intervention, the PMLHC might help in two ways. For patients and providers who felt they had

no more options to try, a comprehensive pain management history could provide an opportunity to revisit old treatments fully, thereby revealing areas where different doses, frequencies, lengths of a trial, or combinations might be tried. A second way the PMLHC might contribute involved engaging the patient in their own pain management efforts. By actively recording their own health data, patients could demonstrate a willingness to engage in the trialing to pain control process.

Communication Accommodation Theory

Researchers have documented the need for improved communication between providers and patients for the treatment of chronic pain (Gordon et al., 2017; Hehl & McDonald, 2014). The CAT is a complex and comprehensive theory that illuminates the social, psychological, and behavioral processes of ways in which humans communicate and interact (Giles & Ogay, 2006). The CAT offers researchers a set of tools to apply to human communication interactions to dissect, inspect, interpret, and try to understand human-to-human communication. The CAT describes human motivations, actions, and behaviors that occur in interpersonal communication. Examples of communication accommodation include how, through the course of a discussion, speakers may begin to speak at similar speeds, adopt the other's accent, or choose simpler or more complex vocabulary based on perceptions of how well the other understands their words.

At the core of CAT are five accommodation strategies. These strategies help researchers define the behaviors observed in communication encounters in ways that help illuminate challenges and problems with communication in many fields and applications (Giles, 2016). The first strategy involves approximation, which one can deploy in either direction; convergence, which happens when trying to be more like the other; or divergence, which occurs when using behaviors that makes one different from the other. Interpretability is the second strategy and involves staying focused on what the other comprehends. The third strategy is discourse

management, which involves the choices a speaker may use, such as taking turns in discussions and selecting the topic to be discussed (Giles, 2016). Examples of the fourth strategy, called interpersonal control, occur when individuals choose to interrupt the other, or specifically use formal or informal titles as ways to remind the other of social statuses. The last strategy involves emotional expressions and includes actions or words that convey reassurance and comfort toward the other (Giles, 2016). In addition to the five accommodation strategies, the full breadth of CAT encompasses seven guiding principles (e.g., communication accommodation is a ubiquitous and fundamental aspect of social interaction, which facilitates coherent interactions), three main adjustment strategies (describes how behaviors of communication can converge, diverge, or be maintained), and is beyond the scope of this review to cover fully (Giles, 2016). However, the sections of CAT that describe mechanisms of intergroup and interpersonal communications are of particular interest in clinical settings because these help researchers understand the communication between providers and patients.

In the medical setting, patients and providers can be viewed as belonging to different groups (intergroup: i.e., high-status provider and patient as a consumer), as well as being two people trying to communicate (interpersonal). Adapting to or away from each other in interactions is key to how humans exist as social creatures with abilities that facilitate coherent interactions and manage social constructs (Giles, 2016). Within the medical setting, people's expectations of each other can influence accommodation; moreover, this aspect is informed by their histories and preferences, as well as their motivations and skills with communication and social interactions. The CAT research in a clinical setting has included patient satisfaction with office visits, use of accommodation strategies as interventions for providers, provider-patient

language barriers, nurse-parent communication in a pediatric hospital ward, and doctors' beliefs about the biological or psychological causes of depression (Giles, 2016).

The first accommodation strategy of approximation is useful in the clinical setting when examining provider and patient choices in communication (Giles, 2016). They can choose to either be like each other (i.e., provider choosing medical versus nonmedical vocabulary to describe issues) or to create distance between each other (i.e., patient preference to call provider by their formal titles to maintain higher status of professional). Adjusting toward the other is referred to as convergence, and adjusting away from the other is called divergence (Giles, 2016).

The second strategy of interpretability occurs in clinical settings when providers focus on what the patient may or may not comprehend (Giles, 2016). A provider who is adept at communicating can perceive how much the patient understood. This type of provider will adjust their choices of vocabulary, word speed, enunciation, and use of diagrams to accommodate the patient's understanding.

Emotional expression involves conveying reassurance and trying to comfort the other, and it has been examined in clinical settings (Giles, 2016). The final strategies include discourse management and interpersonal control. Discourse management involves how the two people take turns talking and who selects the topics of conversation. Interpersonal control involves phrasing questions in certain ways (open-ended versus closed-ended), interrupting each other, and encouraging turn taking. CAT principles state that humans can accommodate an individual when they wish to make their message more understood or the affiliation stronger (Giles, 2016). However, CAT principles also state that the opposite can occur (Giles, 2016).

Hehl and McDonald (2014) investigated the strategies of discourse management and interpersonal control in a secondary analysis of 22 transcripts of provider-patient office visits

regarding the pain management content of the visits. Hehl and McDonald chose these two strategies for examination because these were well suited to being observed in transcripts of the recordings of the office visits. Hehl and McDonald used content analysis to code the pain discussion portions of the transcripts for both the patients and the providers.

The findings, although limited due to a small number of participants, indicated some areas of concern in provider-patient pain management communication (Hehl & McDonald, 2014). In 58.8% of the office visits, patients lost focus on the pain topic, and five patients (22%) failed to discuss their pain, despite reporting a moderate amount of pain to the researchers. Providers' use of discourse management showed that they only opened the pain discussion with an open-ended question that lacked social desirability 33% of the time. Questions that used social desirability were used in polite conversations, and these often prompted simple, polite non-answers (e.g., "How are you today?" with a typical answer of "Fine."). Use of an open ended question without social desirability was found to gather more information from patients (McDonald, Shea, Rose, & Fedo, 2009). In conclusion, CAT helped researchers understand some of the breakdowns in provider-patient communication.

Hehl and McDonald (2014) found that providers might not ask questions in the most productive way, and patients might fail to stay on the pain topic, thereby potentially not divulging complete pain information. By utilizing elements of CAT to examine provider-patient communications during office visits, the vulnerable areas of pain topic communication emerged (e.g., failure to bring up pain topic and failure to stay on topic; Hehl & McDonald, 2014). Interventions that alleviated some of these breakdowns in communication between providers and patients would include helping the patient control the content of information exchanged to ensure that full information was disclosed. One possible strategy could involve having patient-

generated pain management history information already filled out and ready for use during office visits. This aspect might save time and improve patient-provider communication by allowing the patient enough time to give full information. The current project was designed to be a pain communication instrument.

Memory Structure: A Precursor to Life History Calendar Methodology

Finding a reliable way to help people accurately remember and recount their histories is the next logical step when designing a communication instrument to capture historical pain management information. One of the biggest challenges to collecting retrospective data from people is that the act of remembering is an active process that may not always lead to the same information (Neisser, 1986, 1997). Neisser (1986) proposed that memories were structured in nested levels with information of varying intensity or interest levels stored in smaller, related pieces. To retrieve a memory, a person needs to access multiple, nested levels of autobiographical memories. For example, a college graduate may not remember having typed a particular sentence in an essay, but they have confidence that they completed the essay, and they know they used a computer to record it, handed it in, received a grade, passed the course, and graduated. The memory of attending college is made of many layers of nested information from the vaguest idea that the person read assigned readings, typed essays, and attended lectures all the way up to the vivid information that they successfully obtained a high grade in a particular course, graduated with honors, and spent a semester abroad. Neisser (1986) suggested that as a person remembered information, the nature of the nested structure of memories allowed them to fill in blanks or rebuild specific information that might not have been readily accessible. By starting with the easily remembered facts (e.g., a high grade in a course), a person could work backward to remember the topic of a particular essay, and then the experience of sitting up all night writing it (Neisser, 1986).

Memory retrieval can occur in multiple ways, such as top-down, sequential, and parallel (Belli, 2000; Belli, Bilgen, & Al Baghal, 2013). Top-down memory retrieval occurs when memories of lifetime periods (years in college) help to remind one about specific events (a particular course) and do not rely on chronological order (Belli, 2000). Sequential memory recall relies on timelines of the subject of interest and is used when remembering events, such as an employment history. In addition, parallel memory retrieval occurs when cues for memories come from different but contemporary activities, such as remembering job history by recalling relationship changes that occurred around the same time (Belli, 2000). Belli et al. (2013) suggested that calendar interviewing could be designed to target specific memory retrieval styles, and therefore maximize autobiographical recall.

To take advantage of the nested nature of autobiographical memory storage and retrieval, life history interview techniques encourage participants to remember events or time frames that occurred around, near, or at the same time as the events trying to be remembered (Belli & Callegaro, 2009). Researchers have given various names to interviewing techniques of this nature that include LHC (Freedman et al., 1988; Ricks & Harrison, 2011; Youngblut & Broton, 1999; Youngblut et al., 2001), lifegrid method (Berney & Blane, 2003; Nico, 2016), calendar instruments (Glasner & van der Vaart, 2009), event history calendar (Belli, Shay, & Stafford, 2001; Luke, Xu, Mberu, & Goldberg, 2012; Martyn & Belli, 2002), and calendar interviewing (Belli & Callegaro, 2009; Glasner, van der Vaart, & Belli, 2012). However, these techniques were referred to collectively as LHCs in this paper.

Background Information on Life History Calendar Research

The LHC methodology was adapted for use in the current study to help older adults recall their pain management histories. The LHC methodology developed in the social sciences as a method to improve the quality of historical data to be collected from people. LHCs gave

researchers a more natural way to capture retrospective data about the course of a person's life to record the sequence of events (Freedman et al., 1988). Traditional LHCs utilize visual grids or timelines that depict multiple topics over the amount of time being researched. Researchers simultaneously record multiple topics on one grid, which allows respondents to share information fluidly and in any order that they happen to remember events or dates (Freedman et al., 1988).

One of the main concepts within a flow of life events include the transitions when people change from one event to another (e.g., changing schools, moving, and marriage or divorce; Belli, 1998). Researchers using LHCs ask respondents to recall transitions in their lives across the studied topics, which allows memory retrieval to develop from multiple paths (top-down, parallel, and/or sequential; Belli, 1998; Belli & Callegaro, 2009; Freedman et al., 1988). Essentially, LHC techniques exploit the idea that autobiographical memory recall can be enhanced by having people think of other events and activities that have occurred around the same times as the target memories (Glasner & van der Vaart, 2009).

A second way that LHC methodology may improve respondent recall is in the fluid nature of the questions. In an LHC interview, interviewers do not adhere to a strict script (Freedman et al., 1988). Instead, respondents can often see the calendar grid as the interviewer records answers; they can use this as a visual cue and to view previously recorded data. In this way, the questions become more of a "fill in the blanks" exercise, with both interviewer and respondent skipping, asking, and/or answering questions in any order that suits their recall (Belli & Callegaro, 2009).

The need for rich, accurate retrospective data is common to many fields of research, and LHC methodology offers advantages for many kinds of studies. Research using the LHC

methodology has spanned multiple fields, including sociology, psychiatric epidemiology, drug abuse research, social histories, disabilities research, and sexual activity (Belli, Agrawal, & Bilgen, 2012; Belli et al., 2001; Freedman et al., 1988; Glasner et al., 2012; Luke et al., 2012; Ricks & Harrison, 2011; Youngblut & Brooten, 1999). Researchers have used LHC methods to capture quality data that would be either lost or cost prohibitive to capture in other ways. For example, Blane (1996) gathered lifetime data for 70- to 90-year-old participants that included types and working conditions of jobs held, living conditions, and nutrition throughout their lifetimes to understand what might have contributed to chronic lung disease besides a history of smoking.

By giving researchers a reliable way to capture data covering many years, researchers can use the LHC methodology to examine complex topics immediately, rather than wait 20 or 30 years for longitudinal studies to develop. Using LHC methodology, Dawson et al. (2002) collected data on the patterns of sport and recreational activities, job histories, and the types of footwear that participating women had worn over their lifetimes. Dawson et al. compared and contrasted that information with the medical records of participants to understand if there was a cumulative effect of damage to knees or feet from certain types of footwear. As the above examples illustrated, one of the strengths of LHC methodology was that researchers could use it to capture historical data across multiple dimensions in an efficient and cost-effective way to avoid problems, such as participant mortality during longitudinal studies.

One of the possible weaknesses of the LHC method is a reliance on memory recall, which may lead to inaccurate data. However, researchers have shown test-retest reliability and recall accuracy of participants using LHC (Berney & Blane, 1997; Engel, Keifer, Thompson, & Zahm, 2001). Specifically, in their work with migrant farm workers, Engel et al. (2001) repeated their

LHC questionnaires with participants two years in a row, and the authors reported a correlation of 0.82 ($p < 0.05$) for workers with a median of 168.5 jobs over their total work histories. Correlations were highest for apple related work at 0.93 ($p < 0.05$), but then dropped to the next highest for cherry work at 0.43 ($p < 0.05$), which became inconsistent across some of the periods. Engle et al. believed that the retest accuracy was close enough to be useful for examining pesticide exposures and stated that it was an improvement over their previous work using traditional questionnaires.

Berney and Blane (1997) used a LHC interview with people to gather information about their childhood addresses, family health, family living conditions, and fathers' occupations. The researchers compared the information to historical archives from 50 years prior. They found that responses matched to a useful level (plus or minus one unit) in 83% to 100% of the recalls (Berney & Blane, 1997). Such studies showed that with the right questioning techniques, reasonably accurate recall was possible both for a few years of information and longer time frames.

Researchers have also compared techniques between LHC methods and traditional question based interviewing. Belli et al. (2001) directly compared LHC methodology versus standard question list interviews in their retrospective study of social and economic behaviors. They showed that LHC produced higher quality retrospective data, and using the LHC did not increase the costs of running the study. Belli et al. used multiple statistical tests to examine and compare data from each experimental data gathering technique with the previously gathered, known information. For example, the researchers found significantly higher correlations for weeks unemployed between LHC method and known information ($N = 309$, $r = .915$, $p < .001$)

compared to question list method versus known information ($N = 307$, $r = .757$, ns; Belli et al., 2001).

Using correlations, z scores, mean signed differences, and mean absolute differences; Belli et al. (2001) reported that the LHC method produced data that more closely matched the known information across several of the nine measures they studied (e.g., income, employment records, and weeks out of work) compared to the question list method. Although noting that their results were not overwhelming, the authors concluded that LHC methodology produced higher quality retrospective data. They listed that the limitations of their work included the short historical period they examined (only past two years of information), and the source of known information was from traditional style question lists. Belli et al. (2012) also compared retrospective data from LHC interviews with conventional questionnaires on a large group ($N = 626$) to discuss missing work for sickness and disability, and then cross referenced the information to a yearly self-reported panel study of the same information. Belli et al. reported that the calendar instruments they tested had a stronger strength of association with the retrospective data of ($N = 305$, $r = 0.35$, $p < 0.001$) versus the conventional questionnaires ($N = 307$, $r = 0.07$, ns) when those correlations were compared ($z = 3.63$, $p < 0.001$). Belli et al. concluded that their calendar instrument led to higher quality, as well as self-reporting of disability and health statuses of the individuals in their study. These studies showed that information gathered by LHC methods was at least as strong as traditional interviewing methods.

Using face-to-face interviews when conducting an LHC interview allows both researchers and subjects to view the calendar; some have suggested this helps with a subject's recall of information (Martyn & Belli, 2002), but large-scale studies are primarily conducted using telephone interviewing (Belli et al., 2001). While conducting a study to examine the

significant life events of the past five years for a large group of 23-year olds ($N = 900$), Freedman et al. (1998) reported no differences between using LHC with telephone interviews versus face-to-face interviews. For example, respondents gave identical school attendance answers 87% of the time, regardless of which interviewing technique was used (Freedman et al., 1988). This study indicated that LHC methodology could be used in multiple formats (e.g., face-to-face and telephone interviewing).

Computerizing LHC methodology is the next logical step for LHC research. Efforts to computerize LHC have mainly focused on organizing the data and creating an instrument to aid the interviewers in entering respondents' answers as they are interviewing (Belli et al., 2012). However, some researchers have created a self-administered LHC (Arunachalam, 2016; Kite & Soh, 2004). Arunachalam (2016) created a computer system to assist the individual in completing the LHC using computer intelligence; in addition, the system could guide the interview toward more efficient data collection. To date, the system was only tested using interviewers, but the system was designed to learn, and then to be adapted to a self-administered mode in future work (Arunachalam, 2016).

Kite and Soh (2004) created a web-based application LHC that utilized computer intelligence to guide questions about tobacco use. Although currently being used by interviewers, these researchers believed their work was the first step toward building a questioning intelligence program that could allow people to self-administer LHC (Kite & Soh, 2004). Self-administered LHC research would require the collaboration between computer science engineers, health care researchers, and social scientists to develop the potential for this methodology to create cost effective, useful data gathering instruments (Arunachalam, 2016).

Computerized LHC remained developmentally in its infancy, but it was helpful to examine areas where LHC might be applied to begin pilot work.

One pilot study existed that used the LHC methodology to examine pain management issues for patients with osteoarthritis (McDonald & Barri, 2015), and no studies existed that used patient-generated, computerized LHC. McDonald and Barri (2015) conducted face-to-face interviews with 19 older adults with a self-reported history of osteoarthritis using an adapted LHC method to determine if the participants could recall their pain management histories in enough detail to gather clinically useful data. Participants could recall from 2 to 9 different treatment regimens and associated outcomes (McDonald & Barri, 2015). Although the findings should be interpreted cautiously, this pilot study indicated that LHC methodology was a feasible method to collect pain management histories from older adults (McDonald & Barri, 2015). The current study built on McDonald and Barri's (2015) concept to combine the LHC methodology with patient-generated computerized data collection.

Overview of Osteoarthritis Pain Management in Older Adults

Older adults represent a diverse population with a range of physical challenges, and each patient should be assessed fully before making any treatment recommendations (Abdulla et al., 2013). While older adults can differ across the spectrums of health and physical functioning levels, one must recognize that aging is a physiological process, and changes occur as the human body ages. In addition to the aging process, physical differences in older adults can occur through past illnesses or chronic diseases; when combined, these can create additional challenges that providers must face when treating older adults' chronic pain (Fitzcharles et al., 2010). Older adults may suffer greater disability and decreased quality of life compared to a younger person with the same condition due to their decreased mobility, slower rates of healing, and co-morbidities (Fitzcharles et al., 2010; Makris, Agrams, Gurland, & Reid, 2014). Older adults with

chronic pain have more problems with sensory and cognitive impairments, issues with polypharmacy, and gait disorders compared to younger patients (Makris et al., 2014). Physiological changes that contribute to those differences in older adults include decreased renal excretion rates and altered drug absorption rates that occur as the body ages (Makris et al., 2014). Due to the variability within the population of older adult patients, providers must assess each patient and customize treatment options based on the individual (Fitzcharles et al., 2010).

In addition to physical differences, older adults differ from younger adults socially and psychologically. Older adults have a tendency to under report their chronic pain issues because they worry about being perceived as complainers; moreover, they may have the belief that pain is a normal part of aging, and some feel they are not listened to by their providers (Clarke et al., 2014; Thielke et al., 2012). Some older adults believed in the common misconception that being stoic and learning to live with their pain would somehow lead to greater pain tolerance (Thielke et al., 2012). Thielke et al. (2012) described that the opposite was true about being stoic; moreover, living with chronic pain led to depression, decreased coping skills, and sleep disturbances. Not only were older adults at risk of thinking their osteoarthritis pain was a normal part of aging, but also trialing to pain control theory indicated that patients and their providers might feel they had run out of treatment options (McDonald, 2014). The authors emphasize the need for providers to recognize that older adults often under report their pain issues and the importance of maintaining an optimistic attitude about helping older adults manage their osteoarthritis pain.

Successful pain management for any patient requires a personalized, multipronged approach that may include pharmacological, physical, social, psychological, and alternative treatments. However, for older adults, providers must include elements that meet the unique

needs of this vulnerable population (Baumbauer, Starkweather, Guite, & Manworren, 2016; Kogan, Wilber, & Mosqueda, 2016). Thielke et al. (2012) suggested that providers needed to counter common myths and educate older patients that pain was not a normal part of aging. When considering the frailty of some older adults, Abdulla et al. (2013) recommended that pain medications for older adults should be started at lower doses; any changes in dosage should be done slowly; and complementary medications should be used in low dose combinations before resorting to higher doses of any one drug. Although research evidence was not yet conclusive, some additional pain management strategies were found helpful, including massage, acupuncture, assistive devices and braces, and self-management programs (Fitzcharles et al., 2010; Hochberg et al., 2012). Finding pain management treatments and strategies that are acceptable to older adult patients involves patient education, communication, and willingness to tailor treatments to the individual patient (Abdulla et al., 2013; Fitzcharles et al., 2010; Hochberg et al., 2012).

In addition to physical therapy, exercise, and medications, practitioners can employ cognitive or behavioral therapies to help older adults with depression and improve their coping skills (Abdulla et al., 2013). Providers and patients should maintain a positive attitude about the treatment of chronic pain; moreover, providers should educate their patients about ways to improve pain management outcomes (Makris et al., 2014). Researchers have shown that educating OA patients about pain self-management strategies can increase the use of massage, exercise, and breathing exercises; furthermore, patients have reported decreased pain levels six weeks after their education sessions (Parlar, Fadiloglu, Argon, Tokem, & Keser, 2014). Education of patients is challenging for providers in relatively short office visits, but the

importance of teaching people ways to manage their pain must remain a priority due to the devastating and eroding effects that chronic pain can have on people's lives.

The British Geriatric Society Guidance on the Management of Pain in Older People (Abdulla et al., 2013), the American Geriatrics Society guidelines (Persons, 2009), and the Osteoarthritis Research Society International's non-surgical guidelines for management of osteoarthritis (McAlindon et al., 2014) represent three major reviews of osteoarthritis and persistent pain treatment research to guide the treatment of osteoarthritis and pain in older adults. Based on these systematic reviews, the following are the recommended treatments with the strongest research evidence for older adults with osteoarthritis: land-based exercise, weight management, strength training, water-based exercise, and self-management and education (Zhang et al., 2010). Medication recommendations include acetaminophen and topical non-steroidal anti-inflammatory drugs (NSAID) for knee arthritis as the first choice for older adults (Persons, 2009; Zhang et al., 2010).

The list of treatments and medications in the computerized PMLHC included evidence-based treatments, as well as other common treatments that were observed in practice and self-management strategies. Treatments in the PMLHC list included acetaminophen, NSAIDs, cortisone injection, prescribed opioids, glucosamine, chondroitin, exercise, physical therapy, topical agents, joint replacement surgery, and pain management strategies (e.g., positioning, rest, applying heat or cold, assistive devices, and massage). The strategy of the communication instrument involved capturing treatments trials, even though they did not all have evidence-based recommendations for use (Persons, 2009; Zhang et al., 2010).

Pain researchers have recommended using established instruments to assess baseline pain intensity and pain interference with function of participants in research studies. For the current

research, the Brief Pain Inventory Short Form (Cleeland, 2009) was used for each older adult participant. The reliability and validity of this instrument are discussed in Chapter 3.

Patients' Use of Computerized Medical History Collection Instruments

As healthcare industry leaders have adapted to electronic health records, researchers have investigated ways to harness the computer's potential for improved communication and to balance the data from each patient (Lobach et al., 2008). The current project focused on the creation of a communication instrument with the potential for increased efficiency with information sharing and usability in healthcare and research settings. Computers have enabled people to capture, store, sort, and interact with data in large volumes and great detail, but one limiting factor has involved data entry (Shapiro, Johnston, Wald, & Mon, 2012). Data entry is at the core of any computer-aided enterprise; moreover, researchers have often considered it tedious and time consuming (Shapiro et al., 2012). Different industry leaders have found a myriad of ways to interface data collecting instruments and machines to bring data directly into computers; however, modern healthcare providers have to rely on manually entering data for historical information and subjective patient experiences (e.g., experiences of symptoms and level of pain; Shapiro et al., 2012).

The use of computers has entered all aspects of healthcare, including patient entered, self-reported health data and chronic pain self-management websites or mobile applications (Gogovor et al., 2017). Researchers have tested interfaces for patients to enter their own data for usability, which have included audio computer assisted self-interviews (Brown, Swartzendruber, & DiClemente, 2013), lap tops, home computers, personal smart phones, hand held devices, touch screen tablets, computers-on-wheels, digitizer pens, and touch screen computer kiosk stations (Benaroya, Elinson, & Zarnke, 2007; Brahmandam et al., 2016; Chrischilles et al., 2014; Herrick et al., 2013; Sanger et al., 2016; Williams, Templin, & Mosley-Williams, 2004).

In recent reviews, chronic pain self-management applications were focused on educational content, pain management strategies, social support, medication trackers, and symptom logs; only one was found that interfaced with a patient's electronic health record (Bhattarai, Newton-John, & Phillips, 2017; Gogovor et al., 2017; Keogh, Rosser, & Eccleston, 2010). Although not designed to be communication instruments, some of the reviewed mobile applications encouraged patients to call their providers regularly, particularly when contemplating a new pain management approach (Bhattarai et al., 2017). Current websites and mobile applications do not yet have the ability to improve communication directly between providers and patients because these are independent of medical records. The current project focused on helping patients record their own historical pain management data in a computerized format that might have the future ability to interface with medical records or research enterprises.

Patients' pain experiences and responses to pain treatments are recorded when the patient describes what he or she is feeling or what he or she can do (subjective data). Currently, this information is captured manually, either by provider- or patient-generated data. The future of computer-aided chronic pain self-management may include using electronic assessment aids or sensors (for objective data). However, these will most likely be useful in assessing patient functionality (movement trackers) or tracking adherence to medication schedules, which may still not capture the full experience of chronic pain management journeys (Keogh et al., 2010). The development of chronic pain self-management mobile applications remains in its infancy; moreover, researchers must continue to develop and test many facets, including patient involvement and motivation (Gogovor et al., 2017; Keogh et al., 2010). Patient-generated health data are ideally suited to communicate the many aspects of the subjective nature of patients' experiences of pain.

Some of the major issues facing adoption of technologies that will allow patients to enter their own health data into a computer or similar device include technology issues, such as access, available technology, data security and authenticity, lack of industry standards for electronic medical records, and how to operationalize receipts and use of the information at the provider's office (Shapiro et al., 2012). Sanger et al. (2016) studied patient and provider perceived barriers to adopting the use of a mobile application under development that would communicate the wound healing status of post-operative patients. Sanger et al. found that providers worried that it would add a new burden to their office workflow; moreover, providers had a lot of questions about integration of patient-generated health data for clinical uses (i.e., who would answer the patient-generated notifications; how assessments and recommendations would get entered into patients' records; and who has the responsibility of following up on unanswered notifications—patient or provider?). Providers also had concerns about how much information patients should be allowed to share. Providers wanted patient input limited to drop down menus or multiple-choice answers to help condense patient-generated health data into more manageable formats (Sanger et al., 2016). Researchers must consider these concerns as they work to improve the usefulness of patient-generated health data.

Researchers have faced additional challenges on the patient side of the issue, such as health literacy, economic disparities, education levels, experience with computers, access to computer devices, language barriers, and reluctance to adopt new technologies (Shapiro et al., 2012). Grant et al. (2008) found that although 52% of eligible patients reported they used the Internet, only 10% used an available patient portal to interact with their own health records. Research with older adults living in a low-income housing facility showed only 8.6% (6/70 study

participants) could independently use an electronic personal health record, while the rest of the participants required some help from the research assistants (Kim et al., 2009).

For participants ($n = 14$) who completed a satisfaction survey, 92.9% of them had shared their printout with their provider, felt they could share more information, and rated the electronic health record as satisfactory or higher (Kim et al., 2009). Kim et al. (2009) provided computers, training classes, and graduate student assistants in the elderly housing complex where they conducted their study over 33 months. However, they still found the majority of low-income older adults were not in a position to benefit from electronic personal health records, possibly due to poor technical skills, technophobia, and low health literacy.

While developing a mobile application that allowed postoperative patients to communicate about their surgical wounds directly to their care givers, Sanger, Hartzler, Lober, Evans, and Pratt (2014) suggested that patients would only use the technology if they found it easy to use, if it was personalized to their needs, and if it offered a predictable and reliable mode of communication with their providers. The challenge for researchers and developers was to balance the needs and abilities of the patients with the needs of the providers, as providers sought to improve communication with electronic instruments. While technical and human factors appear daunting, researchers have begun to understand the possibilities that emerge when patients are empowered to record their own health information (Arsoniadis et al., 2015; Benarolia et al., 2007; Herrick et al., 2013; Kim et al., 2009; Ruland et al., 2010; Schnipper et al., 2012; Wald et al., 2010; Williams et al., 2004).

Despite these real and potential barriers to patient self-reported health data, researchers have explored the potential for active patient involvement in their health care management (Kim et al., 2009; Wald et al., 2010). Researchers have found patients who chose to use a patient

portal to enter their own data in an electronic journal that was later reviewed by their providers reported better preparation for their subsequent office visit; moreover, the patients expressed that communication was improved with their providers (Kim et al., 2009; Wald et al., 2010). Grant et al. (2008) found that patients with diabetes, who used a patient portal and entered their own health data, were more likely to have a recommended medication change at their next provider visit compared to patients who did not use the portal. Grant et al. found an improvement in participating patients' hemoglobin A_{1c}, which they attributed to a reduction in communication barriers from the self-reported data. No research currently exists that examines electronic patient self-reporting of OA pain management history. Multiple Internet based programs inform or help patients report or manage their chronic pain, but most were limited to current pain symptoms, educational content, and peer support content. Furthermore, none directly communicated with providers or linked to electronic health records (Gogovor et al., 2017; Wilkie et al., 2003). Patient-generated health data has the potential to be a helpful communication aid between patients and providers, but it will be important to develop instruments that are usable by the diverse health care consumer base.

Older Adults' Feasibility of Computer Use

Patient entered health data may offer advantages in reducing communication barriers, providing accurate information, and improving patient engagement in their own healthcare (Arsoniadis et al., 2015; Bren, 2006; Shapiro et al., 2012). The next question for the current project's population was whether older adults would be willing and able to engage in patient-generated health information activities. Brahmandam et al. (2016) studied the willingness and ability of older adults to use a tablet computer in an emergency department to enter some of their clinical information. The researchers found that only 50% of people over 65 years old were willing to try the tablet, and people over 74 were the least willing and least able to use the

devices. However, they found that older adults who had previous exposure to the technology were more willing to try, required the least amount of help, and recorded more accurate answers than those with less technology experience (Brahmandam et al., 2016).

Williams et al. (2004) similarly found that retired, older adults had difficulty with the technology when asked to enter their own medical history information. In focus groups, their participants (all patients at a rheumatology clinic) expressed that for them, manipulation of the mouse was the most difficult part of using the computer (Williams et al., 2004). Yet even with the challenges, Wald et al. (2010) found that a majority of patients felt more prepared for their visits and recommended using a patient portal to augment medical records as a way to improve communication with providers. Older adults may have difficulty using computers for their healthcare needs, but if they can perceive benefits, they will be more likely to try (Kim et al., 2009; Sanger et al., 2014).

Despite the technical challenges, older adults are the fastest growing demographic in computer and Internet use (Nielsen, 2013). In the United States and over the past decades, older adults have learned to use home computers and hand-held devices at an average growth rate of 16% per year (4.2 million Internet users over age 65 in 2002 up to 19 million in 2012). Furthermore, this increasing familiarity should help to reduce reluctance to use computers for health-related activities (Nielsen, 2013). Anderson and Perrin (2016) reported that 59% of U.S. adults over age 65 used the Internet.

Software designers and health information researchers should take care to design interfaces that will be user friendly for people over 65. Researchers have found some design and technology features can help, such as touch screens, ergonomic mouse controllers, larger fonts, un-cluttered screens, and fewer navigation choices (i.e., keep items simple; Herrick et al., 2013;

Nielsen, 2013). Herrick et al. (2013) studied patients' willingness and ability to use a self-administered computer interview during an emergency room visit. The researchers found that older adults (over 65) were the most reluctant age group to participate, but when they did participate, they found touch screens easier to use than digitizer pens. Technology that makes using computers easier, such as larger screens and simple interfaces (i.e., touch screen instead of mouse) should be considered when planning systems for patient entered health data (Vedel, Akhlaghpour, Vaghefi, Bergman, & Lapointe, 2013; Williams et al., 2004). The percentage of older adults willing (and able) to use a computerized health care communication method increases with each year due to new learners and the aging of people who already know the technology.

Summary

Elements of CAT show potential areas for interventions aimed at improving communication between providers and patients, including finding ways to help older adults recall and share complete medical history information. Computerization of health records has rapidly spread to all areas of health care, and there is potential in harnessing patient-generated health data. Patient-generated health data might reduce the time for a provider to take a full patient history, decrease data entry errors, and empower patients to participate in their pain management journey. LHC methodology represented a well-documented method of aiding recall of historical information, including health histories.

Trialing to pain control theory indicates that providers and chronic pain patients reach a point when they feel they are running out of treatment options. The theory shows that the willingness to revisit previously discarded treatment options is one area of hope. Utilizing LHC methodology to help older adults recall past pain management treatments has been shown to produce a timeline of treatments and outcomes. Providing a prewritten history of past pain

management treatments can improve communication between providers and patients, thereby allowing providers to review that history for new treatment options. Older adults should be taught and encouraged to manage their pain regimens because researchers have demonstrated that learning to self-manage chronic pain can improve quality of life for patients.

There were many hurdles to overcome to achieve fully integrated electronic records that have meaningful sections for patient-generated health data, including many human and technological challenges. However, researchers have identified the types of information that can be reliably generated by patients. Developing a self-administered, online PMLHC was one way to explore the pain management histories of older adults, which might have applications in both research and clinical settings.

The next chapter contains a description of the design and methodology of the multiphase study. Chapter 3 will also describe the evolution of the study from three phases to two with a pilot study of the instrument that was developed. Chapter 4 will follow with a presentation of the results. Chapter 5 will complete the study with a discussion of implications and recommendations for future research.

Chapter 3: Design and Methodology

This chapter provides a description of the design and methods of the study. The computerized PMLHC developed is described. Focus group methodology and content analysis technique used in both Phases 1 and 2 is discussed prior to detailing the individual study phase methodology to minimize duplication. Original plans are included for the phases of the study, as well as the revisions (changes to Phase 2 and omission of Phase 3). The rationale for the revised phases is explained.

Study Design Overview

This three-phase study was designed to develop a computerized version of an adapted pain management LHC, and then test its feasibility for use in the primary care clinical setting. A three-phase descriptive research design was chosen to address the following research questions:

1. Is the output from the computerized PMLHC a feasible and acceptable pain management instrument for use by primary care providers?
2. Is the computerized PMLHC a usable instrument for older adults?
3. Is the PMLHC a feasible pain management instrument in the clinical setting?
4. What pain management communication occurs between provider and patient when they use the PMLHC during an office visit?

Phase 1 was designed to test Research Question 1 and was conducted with three provider focus groups. Phase 2 was designed to test Research Question 2 and was conducted with community dwelling older adults.

Originally designed as a focus group study, the data collection methodology of Phase 2 was amended after the first focus group's data were examined. Focus group participants shared that they had made errors in reporting their pain management histories because they had not understood some aspects of the computerized instrument. After review of the data, the

methodology was changed to allow inquiries about each older adult's medical history. Using individual interviews allowed the researcher to ask personal medical history questions to test the validity of the PMLHC content. As Phase 2 progressed, data were analyzed immediately after collection to allow editing of the computerized PMLHC based on older adults' suggestions and the researcher's observations. Saturation was reached after 12 participants were interviewed for suggestions and ideas to improve the PMLHC within the researcher's available resources. Data analysis for the PMLHC content of the first 12 participants revealed that incomplete and inaccurate pain management histories were recorded on the first five versions of the computerized PMLHC. Phase 2 was amended again to allow expanded pilot testing of the final version of the computerized PMLHC to continue examining the validity of the pain management content recorded. The methodology remained the same, but the amendment allowed additional participants. The interview questions remained the same, but the interviews were enhanced by accessing and reviewing the participants' PMLHCs on screen during the interviews.

Phase 3 was originally designed as a feasibility study of the computerized PMLHC in a clinical setting and would have tested Research Questions 3 and 4. After self-administering a PMLHC, older adults would take the printout into their office visits with their participating providers. The office visits would have been audiotaped, and transcripts would have been analyzed for pain management communication content. However, the data from providers in the Phase 1 focus groups indicated that the PMLHC printout was not yet an acceptable instrument for use by providers in the clinical setting. After Phase 1, planning for Phase 3 changed to the concept of an online pilot feasibility test of the computerized PMLHC as a pain management research instrument. However, the expansion of Phase 2 changed the study's trajectory once again due to the need to continue testing the validity of the pain management content recorded by

older adults. Phase 3 was eliminated from the current study to allow the pilot testing of the computerized PMLHC to continue using the Phase 2 enhanced interview methodology. The final research questions after amendments to the study were the following:

1. Is the output from the computerized PMLHC a feasible and acceptable pain management instrument for use by primary care providers?
2. Is the computerized PMLHC a usable instrument for older adults and does the computerized PMLHC collect accurate pain management histories as compared to interview data?
3. Is the computerized PMLHC a feasible pain management research instrument?

Focus Group Methodology

Focus group methodology, as guided by Krueger and Casey (2015), was used in Phases 1 and 2 of this study. Krueger and Casey outlined many suggestions for conducting successful focus groups, which included determining the purpose; planning group composition and size; and developing a questioning route, numbers of participants, and moderator skills. Focus group methodology was chosen because focus groups could produce data with helpful insights and ranges of ideas to capture the behavioral and motivational concerns of the participants (Krueger & Casey, 2015). Focus group methodology aligned with the purpose of this research project, which involved developing and testing the acceptability and feasibility of a computerized pain management communication instrument. Focus group methodology evolved from product development and market research conducted in the business sector over many years; moreover, researchers have successfully adapted it to research applications (Hincapie, Warholak, Murcko, Slack, & Malone, 2011; Krueger & Casey, 2015; McAlearney, Schweikhart, & Medow, 2004). In one-to-one interviews, the researcher risked directly influencing participant's answers through the mechanisms of social desirability, as well as by controlling the questions and the flow of

conversation (van Kleef, van Trijp, & Luning, 2005). In contrast, focus group interviews allowed the attention to shift away from the researcher to remain on the opinions and discussions of the participants (Krueger & Casey, 2015). The researcher hoped that development and usability testing of the communication instrument would be enhanced by group dynamics that could allow providers (Phase 1) and older adults (Phase 2) to brainstorm opinions, ideas, and suggested uses and improvements for the computerized PMLHC.

Planning group composition and size. Focus groups are most effective when made up of participants from a common group or category (Krueger & Casey, 2015). Phase 1 focus groups were comprised of convenience samples of primary care providers (utilizing any combination of doctors, nurse practitioners, or physician assistants) who self-identified that they regularly saw patients over age 65 who had osteoarthritis. This study included multiple types of clinicians in the focus group because of their employment as primary care providers in practices that had older adult patients. The providers shared a commonality based on their type of practice, and they supervised the health care needs of their patients over 65.

A literature search was completed to confirm this study's assumption that mixed providers shared a commonality based on their type of practice. Gudzone, Clark, Appel, and Bennett (2012) conducted successful focus groups containing primary care medical doctors and nurse practitioners to examine communication during weight consultations. Geller (1999) held provider focus groups with medical doctors, physician's assistants, and nurse practitioners to examine roles of primary care providers in rural mental health services. In another study, researchers examined referral to eye specialists in separate focus groups to detect if the information collected varied between the different groups (Holley & Lee, 2010). Results showed medical doctors, nurse practitioners, and physician assistants groups generated almost the same

information about referral processes for eye specialists (Holley & Lee, 2010). The only reported difference was that nurse practitioners and physician's assistants were more willing to learn to conduct follow-up care for eye problems compared to the medical doctors (Holley & Lee, 2010). The literature review provided evidence to support the assumption that successfully combining medical doctors, nurse practitioners, and physician's assistants in a focus group depends on including a topic they had all experienced. In the present study, that topic involved whether they found the computerized PMLHC useful and the suggestions they could make for further development. Phase 2 participants shared the experience of being over 65 years of age and living with osteoarthritis.

Developing a questioning route. When developing a list of questions for a focus group, Krueger and Casey (2015) suggest starting with simple to answer opening questions to encourage participants to speak. The moderator must use clear language, simple to pronounce words, and open-ended questions when possible. Krueger and Casey recommend that the moderator should open the discussion by defining rules for the group and reminding the group to have respect for each other's opinions, thereby allowing all voices to be heard. After using some simple, ice-breaker questions, the key questions should be designed to ask participants about the topics from the study, which are typically the questions that derived from the data for analysis. Moderators should plan to use follow-up questions to keep the conversation flowing and on topic. At the end of the focus group, the moderator should plan on summing the ideas that the group shared to invite any further input or clarification from the group. Having a written outline of opening remarks, topical questions, suggested follow-up questions, and closing remarks can help the moderator stay organized.

Numbers of participants. Krueger and Casey (2015) suggested that the number of focus groups should be three or four with 5 to 8 participants in each group (p. 82). Krueger and Casey recommend a maximum of eight participants per focus group because this number facilitates participant opinions and encourages conversations to generate ideas. The number of focus groups to hold depends on the data collected and the complexity of the topics, but Krueger and Casey propose that focus groups should be conducted until no new information is generated by the groups.

Moderator skills. Krueger and Casey (2015) recommend that the moderator should have strong communication skills, be respectful of the participants, understand the topic being studied, and maintain an open attitude. The moderator must maintain a non-defensive attitude, which could be difficult if the investigator of the study moderates the focus groups. Investigators must be prepared to hear negative feedback about their program or product, as well as to find ways to stay emotionally neutral. Krueger and Casey suggest that the moderator should have an assistant whenever possible to help facilitate the session and take detailed notes. Moderators must have good listening skills and the ability to summarize the topics discussed. Because a novice researcher conducted the current study, the researcher used self-reflection, advisor mentoring, and practice to help train for the role of focus group moderator.

Focus group methodology was chosen for the current study (Phases 1 and 2) to help gather participant opinions and ideas for instrument development. The researcher used Krueger and Casey's (2015) methodology to organize and plan the research. This methodology was instrumental in helping the moderator prepare for the group sessions.

Content Analysis Methodology

In Phases 1 and 2 of this study, the researcher chose the content analysis methodology of Krippendorff (2013) for data analysis of the audiotaped and transcribed focus groups and

individual interviews. Content analysis allows data to be extracted from text in a series of steps that helps the researcher understand and make inferences about the phenomenon or process being studied, while enabling them to understand the context in which the text data exists or is generated (Krippendorff, 2013). For the present study, the researcher anticipated that instrument development would be aided by understanding both the critiques of the participants, as well as how they might envision using the computerized PMLHC in primary care office visits. By examining participants' statements and ideas using content analysis, the researcher highlighted inferences about the feasibility and acceptability of the instrument to both providers and older adults.

Krippendorff (2013) defines the steps of content analysis as unitizing, sampling, recording/coding, reducing, inferring, and narrating. The first four steps are collectively referred to as data making. Unitizing can occur in various parts of the content analysis process and involves both choosing the texts or parts of texts to include, as well as defining the types of units that can not be divided without losing the meaning. For the present study, entire transcripts were examined, and units of data included words, phrases, or statements. The researcher did not use content analysis to examine these units for relationships to each other because the information was discarded as non-data. Instead, inferences were made with the collections of data units. Krippendorff defined sampling as the subsets of information that were used for the analysis to explain what types of texts or which sections of texts were chosen for analysis. The current researcher used excerpts from transcripts of focus groups and interviews that were conducted with the purpose of asking people for their input regarding the instrument being developed.

Krippendorff's (2013) third step method involved recording or coding. Researchers can use coding to apply human intelligence to the data to find the representations that are analyzable

and relatable to the research questions. For the current study, the data were examined for units of information about the computerized PMLHC based on *a priori* criteria that highlighted positive or negative features, missing features, and statements that did or did not support feasibility and acceptability of the instrument. Two trained coders independently coded data using pre-established coding instructions for each phase, and they discussed any discrepancies until they reached an agreement. The specific coding instructions are explained further under the methodology of each phase in the next sections.

The fourth step, reducing, was achieved by finding ways to represent each important unit of data, while avoiding duplications. Examples included compiling a list and noting the frequencies of each response or only collecting each specific type of data once for a list of unique concepts or units of data, regardless of how often each was repeated. For the current study, collecting information about the frequency of responses was not as important as capturing all unique ideas throughout the transcripts. These data were then reduced into clusters of information to describe the range of participants' responses.

Once the units of data were coded and reduced, the researcher must abductively make inferences about the meaning of the data to describe the phenomenon of interest and examine the research questions (Krippendorff, 2013). Abductive reasoning began with observations; from those, the researcher sought the most likely explanation. Through the step of inferring, the researcher attempted to move outside the data to understand the meaning of the data in context. In trying to understand how participants felt about the PMLHC and PMLHC output, these data were grouped into subcategories under the larger clusters of positive and negative impressions. The researcher examined coded data and made inferences regarding support or nonsupport for the feasibility and acceptability of the computerized PMLHC. The final step in Krippendorff's

(2013) content analysis involved narrating, which was necessary to communicate findings and share the results with others. Findings must be comprehensible to others, and these could often include a discussion of the practical significance of the work (Krippendorff, 2013).

Phase 1: Feasibility and Acceptability of Using the Pain Management Life History Calendar: The Provider Perspective

Phase 1 was designed to explore the following research question: Is the output from the computerized PMLHC a feasible and acceptable pain management instrument for use by primary care providers?

Design. The researcher used a descriptive study design, using the focus group methodology (Krueger & Casey, 2015) described earlier, to explore the views of the providers regarding the following:

- What were their perceived value of using the output from the computerized PMLHC during office visits?
- Could they envision incorporating the computerized PMLHC into their practice?
- Did the information from the PMLHC generate ideas to explore for further assessment or treatment changes for them?
- What were their reactions to this type of patient communication instrument (one where the patient presents with a printout of information to be reviewed)?
- What were the suggested refinements for the printout from the computerized pain management instrument to help make it easy to read and interpret for use during office visits?

Sample and setting. Permission to recruit providers from a large, multiple-location, hospital-based medical group was obtained through the researcher's institutional review board (IRB) and the administration of the medical group before approaching the practices to recruit

primary care provider participants. The researcher used convenience sampling to recruit participants through posted and emailed invitations. Multiple focus groups were planned to allow for data saturation. In each of the three settings, a physician volunteered as an informal champion and helped with recruitment efforts and distribution of the invitations. Eligible participants included physicians, nurse practitioners, and physician assistants who spoke and understood English, worked in a primary care setting, and had older adults in their patient population. Two participants were in the first group; two participants were in the second group; and six participants were in the third group. Focus groups were conducted at the providers' offices, in conference rooms that allowed for privacy and for all participants to sit at a table facing each other and the moderator.

Instruments. This researcher created a 12-item demographic form to record information about the provider participants and their experiences with computer use in the clinical setting. Requested information included basic demographics (e.g., age, gender, and ethnicity), professional role (e.g., doctor, nurse practitioner, and physician's assistant), and years of clinical experience. To understand the providers' backgrounds with computer use, the form included four questions about their experiences with electronic health records and which communication technologies they used in their practice (see Appendix B).

Procedure. Approval for the research was obtained through the university's IRB, and then from the hospital's IRB that had oversight of the medical practice used for recruitment of providers. This researcher recruited participants through convenience sampling. Three physicians distributed invitations to participate to their colleagues through office emails, thereby making recruitment successful at those provider offices; in addition, they helped to recruit and schedule the focus groups. The focus groups occurred in quiet, private conference rooms at each

respective medical practice. Informed consents were obtained from each participant at the beginning of the focus group meetings. Focus group sessions were digitally recorded (audio only), and notes were written. A trained research assistant recorded notes during the second focus group.

Once participant completed the informed consent, they filled out the demographic form and received a copy of a fictitious patient's PMLHC (see Appendix C). Providers were asked to use the following clinical scenario: Mary, a 68-year-old retired teacher, had 10 years of painful knees and osteoarthritis; she was diagnosed four years prior. Today, she wanted to discuss the increasing pain in her knees. The printout of Mary's PMLHC (see Appendix C) included five treatment rounds and the outcomes for each treatment type.

The sessions began with introductions of the moderator (researcher) and assistant (at the second focus group only). The moderator began with a welcome statement, a brief overview of the PMLHC, an explanation of the ground rules for the discussion, and then moved to opening the discussion (Kruger & Casey, 2015). The focus group meetings lasted from 29 to 40 minutes. The moderator asked questions, sought clarification on topics as needed, and used a prepared guide for the discussion topics (see Appendix D). Participants were encouraged to converse with each other beyond simply responding to the moderator's questions. Although two of the focus groups were short, all questions were covered. In addition, participants stated they could not think of any further information to add. There was no defined time limit for focus groups, although a group of 6 to 8 people could typically talk for up to an hour (Krueger & Casey, 2015).

The first two focus groups had two participants each due to invitee nonattendance. Krueger and Casey (2015) recommended holding the focus group, even if only a few participants were present. The first two focus groups were planned to coincide with monthly division

meetings of the medical group that expected a large attendance of providers. The focus groups were scheduled for 45 minutes prior to the start of the monthly meetings to maximize convenience for the attendees. Twenty-three email invitations were issued, and follow-up reminder emails were sent to providers for both focus groups. However, attendance for the monthly division meetings was not mandatory for providers, and attendance was low for the two dates chosen, thereby decreasing turnout for the focus groups. For the third focus group, a lunch time focus group was planned, which improved attendance.

Data analysis. The research question asked if the computerized PMLHC was a feasible and acceptable pain management instrument for use by primary care providers. Professional transcriptionists transcribed audiotapes from the focus groups. The IRB approved the transcription company after signing a confidentiality agreement. The researcher analyzed handwritten notes and transcripts using Krippendorff's (2013) content analysis methodology.

The two coders included the researcher and an experienced PhD pain researcher. The coding instructions for the data were predefined, and each coder independently examined the data before meeting to discuss findings. The coders discussed all discrepancies until they reached an agreement. The coding instructions involved examining the data for *a priori* defined categories of information about the PMLHC that included sentences or fragments of sentences. The *a priori* categories involved positive features, negative features, missing features, and statements that either did or did not support feasibility and acceptability of using the PMLHC in a clinical setting. Positive, negative, and missing item statements from the coded data were identified for suggested revisions for the computerized PMLHC output planned for use in the original Phase 3. Coded responses were summarized with frequencies. With the agreement of both coders, reexamination of the coded data during analysis resulted in deletion of two positive

features, conversion of one positive feature to support for feasibility, and five duplicate missing features condensed to two.

Inferences were made using the coded information about the feasibility and acceptability of the computerized PMLHC as a clinical pain management instrument. These coded data were sorted into clusters of related ideas. Phase 1 of the study was designed to capture the input and opinions of providers to guide the development of the computerized PMLHC. One must capture end user opinions and experiences at the beginning of development research. Moreover, demographics of the participants in the focus groups were examined for frequencies of type of providers, educational background, gender, ethnicity, and use of electronic records in their work settings. Additionally, types of computer experiences of participants were described.

In summary, Phase 1 presented the printout of a fictitious patient's PMLHC to providers in three focus groups and asked them for their reactions to the printout's content and layout, as well as for them to imagine using the information during an office visit. This phase in the project sought to understand whether the concept and product of the computerized PMLHC was acceptable to providers and what kinds of changes would make the printout more appealing. The next phase of the study focused on developing the online instrument for older adults.

Phase 2: Feasibility of Using the Pain Management Life History Calendar: The Patient Perspective.

Phase 2 addressed the feasibility and usability of the computerized PMLHC with older adults. This phase was also used to edit and develop the online version of the PMLHC. After editing and developing, the final version of the PMLHC was used for the extended Phase 2 pilot testing.

Design. This phase began as a descriptive study using focus group methodology to address the second research question: Is the computerized PMLHC a usable instrument for older

adults? After the data were analyzed from the first focus group, the study was amended to a descriptive study design using individual interviews with product testing of the early versions of the computerized PMLHC. The methodology was revised to accommodate individual interviews for the privacy to ask questions about each participants' medical histories. The revised methodology also allowed greater observation of the participants, as they answered questions on the computerized instrument. This researcher adapted new questions from the LHC interview method developed by McDonald and Barri (2015). The research question addressed by the change in methodology was the following: Is the computerized PMLHC a usable instrument for older adults and does the computerized PMLHC collect accurate pain management histories as compared to interview data?

Sample and setting. Participants included older adults (age 65 or older) with self-identified osteoarthritis pain for at least one year, who spoke and understood English, and had a basic skill level with using computers (e.g., used email or online shopping). After the university's IRB granted permission for the study, administrators of multiple community senior centers in the northeastern region of the United States were approached as potential recruitment sites. Seven senior centers allowed the researcher access for recruitment. Convenience sampling, snowball, and word of mouth recruitment were used for both the focus group and individual interviews. The researcher printed an invitation to participate in the monthly newsletters of the senior centers and recruited in person. The senior centers also provided private space for the focus group and interviews to take place. One older adult preferred to be interviewed in her home, and the researcher accommodated this request.

Three participants took part in the focus group. Twenty-five older adults participated in the individual interviews for a total of 28 participants in Phase 2. Phase 2 was extended to allow optimizing and testing of the accuracy of the computerized PMLHC

Instruments.

Older adult participant demographic form. The researcher collected basic demographics and clinical information from participants using a 14-question form created for this study. Information requested included age, gender, ethnicity, education level, type of employment (current or previous if retired), marital status, and whether they owned and or regularly used a computer. Participants were also asked if they used electronic communication with their providers, such as email or texting (see Appendix E).

Brief pain inventory short form. As a detailed addition to their basic demographics, participants were asked to fill out the Brief Pain Inventory Short Form (BPI-SF) to capture information about their pain. Persons (2009) recommended that pain be measured using established methods. This 15-item questionnaire measured pain locations; average pain intensity for the previous 24 hours; current pain intensity; the types of treatments being used; and whether their pain interfered with activities, moods, or relationships (Cleeland, 2009). Researchers have widely used the BPI-SF and considered it a reliable instrument for the measurement of chronic pain (Cleeland, 2009). The Cronbach's alpha reliability of the BPI-SF ranges from 0.77 to 0.91 (Cleeland, 1991). In addition, researchers have tested validity of the BPI-SF with different patient populations, and the instrument has consistently shown evidence of the two domains of pain measurement (severity and interference; Kapstad, Rokne, & Stavern, 2010; Lapane, Quilliam, Benson, Chow, & Kim, 2014; Zalon, 2006), including older adult patients with osteoarthritis (Mendoza, Mayne, Rublee, & Cleeland, 2006). Researchers have also

demonstrated validity with correlations at or above $r = .60$ with the Pain Visual Analog Scale and the Western Ontario and McMaster Universities Osteoarthritis Index (Mendoza et al., 2006).

Computerized pain management life history calendar. The researcher created the computerized PMLHC using the Qualtrics Research Suite Software. The instrument was adapted based on the pain management LHC methodology that McDonald and Barri (2015) used in a pilot study. Participants were asked to describe their history of osteoarthritis pain treatments from when their pain first started to present day. The pilot study adapted the LHC interview techniques, and participants were asked to think about times in their lives when pain or discomfort affected their lives. This process helped them remember details about their pain treatment histories (McDonald & Barri, 2015). In the computerized PMLHC, participants were asked the following:

To begin, please think about when you first experienced pain from your arthritis. As close as you can remember please tell us the year (and month) you can remember the pain starting. It might help to remember other events in your life that were happening at the same time that your arthritis pain first needed treatment.

Participants next identified the affected body part, and then chose treatments from drop down menus. The British Geriatric Society Guidance (Abdulla et al., 2013), the Osteoarthritis Research Society International's non-surgical management of osteoarthritis guidelines (McAlindon et al., 2014), and suggested additions from participants in Phase 2 informed the choice of listed treatments on the management of pain in older people. In a series of tables, participants then described the results that they experienced with each treatment choice for both pain outcome and functioning with pain outcome.

To capture rounds of treatment regimens, participants were prompted with the following: “As a next step, please think about when you changed your treatment regimens (it may be helpful to think about events in your life to help you remember the year and month when you changed regimens).” Participants could record up to 10 rounds of treatments in the final version of the instrument. Ten rounds were chosen as the maximum by adding one more than the maximum of nine rounds of reported treatment regimens found in McDonald and Barri’s (2015) pilot study that used LHC methodology. At the end of each round of treatments, participants could choose either to record another round or to end the study by choosing “this was my last time frame and reflects my current treatment regimen.” The final version of the instruments included next and back buttons to allow editing of information if the participant remembered something to add or delete. Screen shots of the final version of the computerized PMLHC (Live Version 7) are available in Appendix F.

Seven versions of the instrument were used during data collection in Phases 2. PMLHC Versions 6 and 7 only differed by one sentence in the instructions that asked participants to “please remember that physical activity is considered a treatment, too.” This final addition that emphasizes exercise occurred after additional reflection about the data from Participants 1 through 13a. Participants 13a, 14a, and 15a had already been tested with Version 6 (no exercise emphasis), and one had not included exercise as a treatment. The researcher hoped that adding the exercise emphasis would help participants remember to include exercise as a treatment. In the enhanced interview, Participant 13a revealed that although he or she forgot to include exercise, the rest of the PMLHC was correct. Therefore, Participants 13a, 14a, and 15a were included in the pilot test. The sixth and seventh (final) versions of the PMLHC were pilot tested

on 12 older adults to explore the contents and accuracy of the pain management histories that they independently recorded.

One of the challenges of creating the PMLHC on an existing survey platform was the limitation of how data could be printed or displayed on screen for each participant. The Qualtrics Research Suite Software was designed to export data in aggregate formats, while allowing researchers to examine data across the answers using statistics software; the software was not designed to examine ways in which individual participants answered the questions. The Qualtrics software did not have an option to edit the format of the output data for individual participants. Therefore, to produce a printout of each PMLHC, the researcher had to export each set of data to an Excel spreadsheet, and then apply a specially prepared Excel Figure Creator to transform these data to a custom designed timeline format.

The complexity of creating an Excel Figure Creator was beyond the skills of the researcher and required the help of a computer science expert who volunteered some of his/her time to assist. The process of reprogramming the Excel Figure Creator was laborious and became unsustainable once the computerized PMLHC underwent rapid edits and new versions during Phase 2 of the study. Additionally, once Phase 3 was eliminated to allow additional PMLHC pilot testing with Phase 2 methodology, the project no longer needed to produce the printout for each patient. Moreover, all subsequent PMLHC output data were examined manually in the raw output format available in Qualtrics.

Procedures.

Focus group procedure. The focus group was held in the computer room of a community senior center. The center allowed the room to be reserved to ensure privacy for the discussions. Computer stations for each participant were prepared by the researcher and the trained research

assistant prior to the arrival of the participants. The computerized PMLHC instrument was queued to the first screen on each of three computers.

Informed consent was obtained from each participant prior to handing out the BPI-SF and the demographic form. Participants were given as much time as they needed with the forms before moving on to the next step. When they indicated readiness, all three participants proceeded to fill out the computerized PMLHC that had been queued. Participants were encouraged to fill in the information independently but were also allowed to ask questions for assistance if needed. When each participant finished their PMLHC (less than 10 minutes each), all chairs were turned to face each other in a circular fashion to facilitate conversation.

The moderator (researcher) began the focus group discussion as the research assistant started the audio recording device and took notes. The researcher followed the focus group methodology of Kruger and Casey (2015). The moderator opened the discussion by asking, “Please think about the program you just used to fill in your pain management history. What are your first thoughts about the program?” The moderator then continued to ask questions to seek clarification on topics as needed. For example, the moderator asked, “What do you see as positive features? What kind of challenges did you face while trying to fill out your PMLHC?” Questions derived from a prepared list of discussion topics (see Appendix G). The focus group discussion lasted approximately 20 minutes.

During the focus group discussion and when reviewing the transcripts and data, the researcher found the initial version of the computerized PMLHC did not accurately record the pain histories of the three participants. Through the course of the focus group conversation, the participants spontaneously revealed details of their treatment histories. The participants expressed that they had misunderstood parts of the instrument, had missed items, and had not

meant to record data in the way that they did. After thorough review of the data, the methodology was changed to individual interviews to allow more in-depth questions about personal treatment histories and to facilitate edits and retesting of updated versions of the instrument. University IRB approval was obtained for the amendment before any further recruitment or research was completed.

Individual interviews procedure. Individual interviews were all conducted in a private room in a community senior center, except for one interview that was conducted in the participant's home at her request. A laptop computer (with 14 inch screen and a USB ergonomic mouse controller) was set up before the participant arrived, so that the first screen of the computerized PMLHC was queued when needed. Informed consent was secured before giving the participant the demographic form and the BPI-SF to complete. Once paperwork was completed, the participant began on the computerized PMLHC; they received as much time as needed to complete the instrument. The participant could ask questions, and the researcher remained in the room in case there was difficulty with the computer or the instrument. Notes were taken about issues participants had while using the instrument.

When the participant finished the PMLHC, an audio recorder was turned on, and the interview began. The researcher conducted the interviews guided by a list of discussion points and questions (see Appendix H). The first half of the interview focused on asking questions about each person's thoughts and suggestions for the computerized PMLHC that was just filled out. Each participant was asked to describe both positive and negative features of the PMLHC and what he or she would or would not change. The second half of the discussion utilized a modified LHC interview technique using the following opening question:

Starting from when your osteoarthritis pain began, tell me in the order of occurrence all that you did to treat your pain, including self-treatment, seeing a provider, problems with the treatments, surgery, and anything else that you did to try to relieve your pain up to the present time.

Each participant was also asked to identify reasons for his or her actions. The participant was then asked if each treatment decreased, increased, or did not affect his or her pain level. Additionally, for each treatment recorded, the participant was asked if his or her pain that interfered with functioning increased, decreased, or stayed the same. Throughout the interview, neutrally worded questions were used to elicit more detail as needed. The researcher also took hand-written notes. The rationale for the second half of the interview was to capture the pain management history of the participants to be used and then compared to the computerized self-generated PMLHC that each participant filled out. The researcher hoped that the face-to-face interview would be usable as the benchmark of pain management history to check the quality of the computer captured data. Eight participants were interviewed using this full face-to-face life history interview.

After eight participants, ongoing analysis of the coded data indicated clinically significant discrepancies between the pain management histories, as collected by computerized PMLHC compared to the face-to-face interviews. Major errors in the pain management timelines were noted, and it was not possible to discern if the errors stemmed from the participants using the computerized PMLHC or from problems with the face-to-face interviews. After careful consideration of the novice skills of the interviewer with face-to-face life history interviews, an additional tactic was instituted. The researcher accessed the computerized PMLHC and used it as a reference during the second half of the interview. The interviewer then used the recorded

information to prompt the participant about his or her pain management history to obtain a complete history. Sixteen participants were interviewed with this enhanced interview technique.

Data analysis. Data from both the focus groups and the first half of the individual interviews were analyzed using the same criteria and were combined for the data analysis. Data included the transcripts of the audio recordings, hand-written notes, and the outputs of the PMLHC from each participant. The researcher analyzed hand-written notes and transcripts using Krippendorff's (2013) content analysis methodology. The data from the focus group and the first half of each interview were examined and coded for units of information about the PMLHC. These units indicated positive features, negative features, missing features, and statements that either did or did not support feasibility of using the computerized PMLHC. Data analysis from the participants was used to revise and refine the computerized PMLHC, and the revised versions were used in subsequent interviews (four versions were tested in these cycles). Using the coded information, the researcher made inferences about the appropriateness and feasibility of the PMLHC as a pain management instrument.

From the second half of each individual interview, the researcher examined data for clinically relevant missing or incomplete data in the computerized PMLHC. Elements of each participant's pain management history were compared across the computerized version, and the interviews gathered information to make inferences about the accuracy of the PMLHC as a patient-generated health data communication instrument. Each computerized PMLHC was examined, and inaccuracies were reported in detail. Discrepancies found included errors of omission, errors in timelines, ambiguous answers (multiple treatment outcomes chosen for treatment choice), or missed outcome notations. Demographic information was examined for

frequencies, and the mean pain intensity and mean pain interference with function were computed from the BPI-SF to describe the study sample of older adult participants.

In summary, Phase 2 involved an evolving phase of the study and was adapted when the data analysis inferred that change was necessary. Phase 2 was designed to collect data that could be analyzed as these were gathered to allow edits to the computerized instrument, and then retesting of the new versions. Phase 2 was first designed as a focus group study but was changed to individual interviews when major errors were detected in the computerized PMLHC of the subjects. Phase 2 was redesigned to involve a series of personal interviews that enabled discussion of participants' medical histories.

While analyzing data by comparing the face-to-face LHC interviews with each participants' PMLHC, major errors were present in the information gathered. It was not possible to tell if the errors were with the computerized PMLHC or the interview technique. After personal reflection and a discussion with a major advisor, Phase 2 was adjusted to allow the face-to-face interview to include viewing the information from the computerized PMLHC. This aspect allowed one to direct follow-up questions toward determining the accuracy of recorded pain management information.

The original design of the study included a third phase meant to test the final version of the computerized PMLHC in an online pilot study. However, data saturation for edit suggestions to the computerized PMLHC did not occur until after the twelfth participant (three from the focus group and nine from the interviews). Therefore, Phase 3 testing was considered unadvisable due to the inaccuracy of the computerized PMLHCs for the initial 15 participants. It was determined that Phase 2 should be expanded to continue testing the accuracy of the final version of the computerized PMLHC. An amendment to the study protocol was attained to allow

recruitment of 10 to 20 more participants in Phase 2. In this way, the overall study was refocused on the development of the computerized PMLHC, and the proposed Phase 3 pilot testing of the instrument was eliminated. Thirteen participants completed face-to-face interviews using Version 7 of the computerized PMLHC.

Rigor

For Phases 1 and 2 of the data collection, the researcher ensured that focus groups and interviews were conducted in a private setting, with the door closed to ensure a quiet space for the conversations to occur. During the focus groups, the moderator set the expectation that all views should be treated respectfully and did not note disruptive or rude behavior. Notes were taken during and after each focus group and participant encounter. For relevancy and logic, a content expert (i.e., primary care nurse practitioner) reviewed the questions used during the provider focus groups. The moderator listened carefully during focus groups and asked for clarification as needed.

Throughout both phases of the study, two trained coders independently coded (where appropriate) the data. In addition, they reviewed and analyzed these data. The two coders compared their coded data and resolved all discrepancies through discussion until they reached an agreement. Moreover, the researcher maintained a journal of notes, ideas, questions, and problems as the study progressed.

Summary

This research study was originally designed to create, test, and pilot a unique patient self-generated pain management history instrument in an online setting. The study began with the concept of developing a clinical application but changed after the analysis of Phase 1 data revealed that providers did not find the output of the instrument acceptable in the clinical setting. As a result, the researcher refocused the study to maximize the development of the computerized

PMLHC for use as a research instrument. Phase 2 of the study was designed to allow the testing and developing of the online PMLHC instrument with older adults. Focus group methodology was chosen to gain feedback and insights from older adults regarding the feasibility and usability of the computerized PMLHC; however, after the first focus group, data analysis and field notes showed that older adults struggled with the input of their pain management histories. Phase 2 was amended and changed to allow individual interviews with older adults. Interviews were planned to allow the researcher to conduct a verbal PMLHC interview and use the information to compare to the patient-recorded PMLHC. A third phase was originally planned to pilot test the developed PMLHC in a clinical setting but was subsequently omitted to allow further data collection in Phase 2. This evolution of the study facilitated the testing of the final version of the computerized PMLHC.

Chapter 4 presents the data collected in Phases 1 and 2. Data for Phase 2 are discussed in two parts: (a) Phase 2, Part 1 and (b) Phase 2, Part 2. Data are also presented that shaped the edits of the PMLHC versions. Chapter 5 contains a summary of the results, the recommendations for future research, and any limitations present in the study.

Chapter 4: Results

This chapter presents the results from Phases 1 and 2. The characteristics and demographics of the study participants are described, as well as the content analysis results from the transcripts from focus groups and individual interviews. The results from Phase 1 showed the reactions and opinions of the providers regarding the printed PMLHC output. The results from Phase 2 had two components. The first component indicated older adults' impressions and suggestions regarding acceptability and feasibility of the computerized PMLHC. The second component showed the contents of the pain management history that the older adults recorded to examine the quality and accuracy of data recorded via the PMLHC. Phase 2 data analysis occurred while data were being collected, and the results were used to edit the PMLHC so that new versions could be tested in the next round of data collection. Seven versions of the instrument were developed and tested. Data saturation for viable edit suggestions was reached after interviewing 12 participants, and the last (sixth and seventh) versions of the instrument were tested on 12 additional participants to pilot test the final PMLHC.

Phase 1: Feasibility and Acceptability of Using the Pain Management Life History Calendar: The Provider Perspective

Provider characteristics. Three focus groups occurred in Phase 1. Ten providers ($N = 10$) participated in the focus groups (two in the first, two in the second, and six in third). All 10 providers were recruited from a large university affiliated, multisite medical practice. Nine (90%) medical doctors and one (10%) nurse practitioner were recruited from three different offices of the large practice. Ages of participants ranged from 41 to 56 years ($M = 50.3$, $SD = 5.60$). The number of years in practice ranged from 4 to 27 years ($M = 17.6$, $SD = 7.78$). Eight (80%) participants identified as White, non-Hispanic; one (10%) as African American; and one participant had missing data. All ten (100%) participants reported they used electronic medical

records (EMR) with a range of 4 to 15 years ($M = 6.45$, $SD = 4.58$) of experience using EMR. Seven (70%) participants reported they used email to communicate with patients (e.g., messages within health record portals), and three (30%) participants reported using other forms of electronic communication with patients (e.g., text messages).

Phase 1 content analysis results. Phase 1 addressed the following research question: Is the output from the computerized PMLHC a feasible and acceptable pain management instrument for use by primary care providers? The coded data showed 22 positive features, 16 supportive of feasibility, 21 negative features, 19 not supportive of feasibility, and 15 missing features and ideas for PMLHC development. These data were then examined and sorted into clusters of related sentiment (affirming or areas of concern). Through repeated sorting of the data, patterns emerged of clusters with subcategories that helped organize the opinions of the participants. The findings are reported in summarized statements using the original coding categories as assigned to the overall cluster title.

The focus group participants examined a printout of a fictitious patient's PMLHC (see Appendix C), and then discussed their impressions and ideas with each other and the moderator. The focus group discussions included a section that asked providers to imagine a future version of the PMLHC integrated into electronic health records. Participants also discussed the potential for patient portals that would allow patient generated PMLHC data to link directly to medical records. Therefore, some of the data reflected positive features and statements that were supportive of feasibility of a potential, future version of the computerized PMLHC. Table 1 and Table 2 illustrate the separation of data based on the future PMLHC versus the current version of PMLHC for positive features (see Table 1) and for statements supportive of feasibility (see Table 2). One had to consider the limited resources for technological support for the overall project

when examining these results to determine the feasibility of using the computerized PMLHC and the output in a clinical setting for the originally proposed Phase 3.

Using Krippendorff's (2013) method for reducing and clustering the data, the following three clusters developed: (a) PMLHC affirmations, (b) areas of concern, and (c) missing features and ideas for PMLHC development. Data in the PMLHC affirmations were sorted into two subcategories called (a) potential advantages of a computerized PMLHC and (b) improved communication to support collaborative provider-patient relationships (see Table 3). Data under areas of concern fell into the following three subcategories: (a) dislike of concept and output format, (b) patient challenges, and (c) workflow challenges (see Table 4). The third cluster, which included the missing features and ideas for PMLHC development that participants noted, included three subcategories called (a) need for assessment of patient perceptions and goals, (b) PMLHC output, and (c) optimizing electronic health record capabilities (see Table 5). Examples of direct quotes used to support each subcategory can be found in Tables 3, 4, and 5. For the subcategory, data are presented in a summarized format in the following sections.

PMLHC affirmations.

Potential advantages of a computerized PMLHC. Positive features that the participants discussed included ideas about the potential to leverage the power of computers. Providers discussed the possibility that a computerized PMLHC could be useful if linked to the electronic medical record. Providers suggested that patients could easily access and update their history, and providers liked that the program provided the lists of treatments and medications to help patients remember details. Finally, the providers stated that a positive feature involved computers taking potentially lengthy patient histories and distilling these down to short, visual timelines or grids, thereby making the PMLHC simple for providers to use.

Statements coded as supportive of feasibility included those that discussed the potential information technology advantages of having a computerized PMLHC become part of the electronic health record, where patients could record their pain management history. Providers envisioned patients using either their own device to enter information or offering a tablet in the office waiting room. Providers felt that the drop-down menus would be advantageous to cue patients' memories; moreover, having the form filled out ahead of time and already in the electronic medical record would save the provider time.

Improved communication to support collaborative provider-patient relationships.

Positive features that help to engage patients as partners in their care included the concept that patients would provide their perceptions of their histories when they filled in their PMLHC. Providers saw patient generated health data as partnering with patients because the alternative was that the provider would have to ask all the questions. Additionally, providers thought that having to fill in the information ahead of time might help patients be more mindful during the office visit.

Providers discussed positive features that had the potential to improve communication and help build provider-patient relationships. For example, providers imagined using the review of the printout as a place they could begin their office visits; in addition, knowing what patients had tried in the past would help direct their discussions. Providers stated that a thorough pain management history would help direct them to the supplemental teaching information to benefit the patient. Finally, providers stated that repeated use of the PMLHC over time could help them build rapport with patients and show they were interested in the patient's pain management.

Supportive of feasibility statements included provider ideas that the PMLHC could heighten collaboration between providers and patients. Providers liked the idea that patients

filled out the form ahead of time, which would allow the patient to review their own history, and therefore be better prepared for office visit discussions. Providers also thought that using the PMLHC output form would allow them to focus their questions better. Providers expressed that the PMLHC could be incorporated into the follow-up workflow for their chronic pain patients; furthermore, the convenience of having pain management history already outlined for the patients would set them up for success. Providers felt that the PMLHC was a unique instrument that collected all the patient's pain management history into one, convenient form. Providers expressed that they had not seen any instrument like it before.

Areas of concern.

Dislike of concept and output format. Providers identified negative features of the PMLHC output when they described it as overwhelming. Several providers expressed that for their style of practice, the PMLHC output went too far in history and did not add value to assessing the patient's current situation. These providers felt inundated with patient data already, and therefore wanted a short list of treatments that had been tried in the past, listing the ones that worked and the ones that did not work.

Additional negative feature comments centered on the format of the output with sentiments that the printout was confusing; the information was too diffused; and the color coding made it difficult to read. Additionally, providers wanted to know when a treatment was actually stopped because the output only showed that it was used in one round of treatments and was not used in the next round a few years later. Some providers did not want to look at the dates; instead, they preferred only information about the treatment outcomes (i.e., did it work or not). Nonsupport of feasibility included providers who found the form to be overwhelming and

stated they were unsure what to do with the form. Providers said they might prefer a different format (perhaps a grid), but some reiterated they would prefer less information overall.

Providers noted some negative features of the PMLHC that included concepts that the instrument was not designed to provide; however, the data were reported there to demonstrate the breadth of the focus group conversations regarding pain management challenges. Providers felt that the PMLHC output was missing patient perceptions of each treatment round, had no information about patient's baseline functioning levels, and had no information about adverse side effects the patients experienced. Additionally, providers noted that the PMLHC output did not include information on patients' levels of pain and did not seem to have any place for patients to explain why they changed treatments.

Patient challenges. The negative features of the PMLHC concept discussed by providers included the worry that patients might “have difficulty with this.” Providers were concerned that patients would not understand generic, medical terms, such as “NSAIDS,” and would not understand how to rate “functioning.” Providers suggested that patients would not remember the dates that treatments were used. Finally, providers worried they might disappoint patients who filled out the PMLHC ahead of time if they subsequently failed to discuss the contents during the office visit.

Statements coded as nonsupport of feasibility included providers' discussions about the challenges that many of their current patient population would face when trying to record their own health data (i.e., older adults' lack of computer expertise, lack of access to computers, language barriers, and medical illiteracy). Providers noted that patients generally did not use their current electronic health record portals. Providers feared that only highly motivated and well-educated patients would be willing and able to take advantage of the PMLHC.

Additionally, providers did not believe that patients would remember enough detail to fill out the PMLHC.

Workflow challenges. Statements of nonsupport of feasibility included providers' worries that they would have to spend extra time going over the patient responses to gain clarity, and this could take up valuable office time. Providers expressed the need to enhance the output to be something "super-simple" for them to process quickly. One provider also expressed that the amount of time spent using the form and information would depend on the patient. In other words, the PMLHC might not get discussed if the patient was not likely to return for follow-up appointments.

Missing features and ideas for PMLHC development.

Need for assessment of patient perceptions and goals. This subcategory was characterized by providers' preferences when assessing chronic pain patients; some of their ideas appeared beyond the scope of the PMLHC. Providers wanted the PMLHC to contain a section about the patients' perceived barriers to improvement to guide patient reflections about their pain management journey. Additionally, providers felt the PMLHC should include a section that allowed the patient to select goals for their pain management. Finally, providers wanted to know patients' overall perceptions of how their pain was addressed in the past. Providers discussed that this information was important to help them manage chronic pain patients' expectations.

PMLHC output. Suggested edit ideas included changing to a grid format, adding start and stop dates for each treatment instead of expressing these as rounds, and using pluses to allow patients to describe degrees of pain relief (e.g., +, ++, and +++). Some providers suggested that changing to date ranges might be simpler for patients to remember (e.g., in the last 5 years or 10

to 15 years ago). Finally, providers preferred to know exact medication or items used, instead of categories or generic terms (e.g., Aleve, instead of NSAID, and cane, instead of assistive device).

Optimizing electronic health record capabilities. The final subcategory of ideas and missing features derived from the section of the focus group discussions that asked providers to imagine the future applications of the PMLHC. Providers suggested that patients should be allowed to update the PMLHC periodically as their histories changed, and the system should alert the providers of such changes. Providers suggested that the electronic health record might send an email or a message when a patient entered new information; moreover, the record could highlight the new information with a different color or an asterisk to alert providers. Finally, providers wondered if the system could be automated to send a prompt to chronic pain patients who made an appointment, thereby reminding them to update or fill out their PMLHCs.

Phase 2: Feasibility of Using the Pain Management Life History Calendar: The Patient Perspective.

Phase 2 was designed and amended to answer the following research question: Is the computerized PMLHC a useable instrument for older adults and does the computerized PMLHC collect accurate pain management histories as compared to interview data? Therefore, data from Phase 2 comprised of multiple parts, including participant characteristics, content analyzed transcribed audiotapes of focus group and interviews, and the contents of participants' PMLHCs. Part 1 of the content analysis entailed the participants' impressions and ideas about the computerized PMLHC; these data were collected in both the focus group and the individual interviews. Part 2 of the content analysis data, collected during enhanced individual interviews, included information that helped examine the accuracy of the pain management history recorded in each participant's PMLHC.

Participant characteristics. A total of 28 community dwelling older adults participated in Phase 2 with one focus group (three participants) and 25 individual interviews. Volunteers were recruited from six senior centers and by word of mouth. Data from four participants were not used in the analysis due to (a) an inability to fill out the PMLHC on the computer independently (two participants), (b) a lack of any arthritis treatments (one participant), and (c) an inability to follow PMLHC written instructions (one participant). A total of 24 participants (combined three from focus group and 21 individual interviews) were included in Phase 2 analysis (see Figure 1). Participants ranged in age from 65 to 92 ($M = 73$, $SD = 6.56$), with 19 (79%) females and 5 (21%) males. Participants reported marital status as 10 (41.7%) married, six (25%) widowed, five (20.8%) divorced, and three (12.5%) never married. Twenty-three (95.8%) participants were White, non- Hispanic, and one (4.2%) participant self-identified as “other.” Twenty-one (87.5%) participants were retired, and three (12.5%) reported they still worked (one worked full-time outside the home; one described herself as a full-time housewife; and one worked part-time as a cashier).

A total of 17 (70.8%) participants reported they did not have a total joint replacement. Of the seven (29.2%) participants with total joint replacement surgeries, three had multiple joints replaced; three had a single joint replaced; and one had no data reported. When asked how often they talked to their providers about their arthritis pain, 16 (66.7%) participants responded with time frames ranging from every three months to yearly; four (16.65%) participants reported that they never did; and four (16.65%) participants had no data for this question. Twenty-one participants completed a Brief Pain Inventory Short Form and reported combined mean pain intensity scores ranging from 0.8 to 10.0 ($M = 3.9$, $SD = 2.71$) and mean pain interference scores ranging from 0 to 7.3 ($M = 2.5$, $SD = 2.07$). The mean pain intensity scores for the four different

time frames evaluated were worst pain ($M = 4.7$, $SD = 3.07$), least pain ($M = 2.9$, $SD = 2.91$), average pain ($M = 4.1$, $SD = 2.80$), and pain now ($M = 3.1$, $SD = 2.74$).

Twenty-two (92%) participants reported they owned and regularly used a computer, smart phone, or tablet, and only two (8%) reported they did not own or regularly use these devices. Of the 22 participants who owned devices, four (22.2%) did not provide details, but the remaining 20 (83%) device owning participants collectively had 14 computers (desk top or lap top), eight tablets, and 13 smart phones. Participants reported they used their devices for various tasks, such as shopping, research, personal business, email, social networking sites, banking, news, calendars, texting, and games. When asked if they used any electronic methods of communication with their provider, most participants (79%) reported they did not, but five (21%) participants reported they communicated electronically with their providers using email, health record portals, texting, or instant messaging.

Phase 2, Part 1: What did participants think of the PMLHC? Content analysis of the transcribed audiotapes identified comments as positive features, negative features, statements supportive of feasibility, statements non-supportive of feasibility, and missing features (e.g., ideas for PMLHC development). Older adult comments were coded, and then reduced into the following three clusters: (a) PMLHC affirmations, which contained five subcategories (see Table 6); (b) areas of concern, which contained five subcategories (see Table 7); and (c) missing features and ideas for the PMLHC (see Table 8). The PMLHC affirmations cluster included (a) general positive comments, (b) liked electronic health records, (c) PMLHC was thorough, (d) believed the PMLHC to be helpful, and (e) increased older adults' self-awareness of pain management. The areas of concern cluster contained (a) general negative comments, (b) dislike

for computers, (c) difficulty filling out the PMLHC, (d) does not tell the whole story, and (e) difficulty remembering details.

PMLHC affirmations.

General positive comments. A total of 16 (66.7%) participants contributed 24 positive comments that expressed generalized positive impressions of the computerized PMLHC, describing the program as easy to follow, excellent, well-planned, simple, clear, and non-intrusive. Most of the general positive comments were coded as positive features, but two were coded as supportive of feasibility because these expressed that the instrument was clear, easy to maneuver, and self-explanatory.

Liked electronic health records. Feasibility and acceptability were supported by older adults who expressed that they liked computers and trusted electronic health information. Three (12.5%) older adults responded that they felt computers were safe, and these could save time in office visits. These three older adults felt that filling the PMLHC out ahead of time would be a good thing; in general, electronic health records offered advantages over old paper records because providers could refer to previous health care information.

PMLHC was thorough. Six (25%) older adults expressed that they found the questions, treatment options, and medication lists to be inclusive and thorough. One (4%) older adult discussed that she enjoyed filling it out and that it asked her everything about her problem. Additionally, older adults shared that the PMLHC captured the nuances of what they experienced, including function and pain levels.

Believed the PMLHC to be helpful. Four (16.7%) older adults felt that the information gathered by the PMLHC had the potential to be helpful. One (4%) older adult thought that the PMLHC helped by sorting through treatment histories and communicating that information to a

provider, who could then validate patient experiences. As a communication instrument, another older adult discussed how the PMLHC could help gather useful information.

Increased older adults' self-awareness of pain management. The PMLHC helped older adults reflect on treatments they tried, and then wonder what else could be tried. One (4%) older adult discussed how the PMLHC made her think of when her symptoms first started. Another older adult felt that the exercise of filling out the PMLHC helped raise her awareness of what she was “actually doing” for her pain management. They developed questions they would like to ask their providers, such as “What other things could be done?”

Areas of concern.

General negative comments. Seven (29.2%) older adults contributed eight about ways in which the PMLHC was vague, repetitive, and restrictive. One (4%) older adult wished that the questions were different because these “kind of boxed you in.” She would prefer to tell her history in her own words. Another older adult also stated that the PMLHC was restrictive because she could not describe her symptoms in detail, instead she had to generalize. One (4%) older adult worried that patients using the PMLHC might not be acceptable to providers because in her experience, providers were resistant to something new unless they recommended it.

Dislike for computers. Although they each had basic computer skills, six (25%) older adults expressed that they did not really like computers for their medical information. These patients suggested they did not trust computers; they worried computers were not secure; and they would rather have paper documentation to bring home. Older adults had concerns about the privacy of their information on the computer and felt uncomfortable revealing medical information on the computer. Another older adult stated, “I hate computers.”

Difficulty filling out the PMLHC. Five (20.8%) older adults experienced difficulty when filling out the computerized PMLHC and expressed they did not understand it, failed to read instructions, and needed help to understand some parts. One (4%) older adult was unsure how to define time frames and wondered if it was supposed to be every 5 years, every decade, or something else. Another older adult realized she made errors in her data entry and did not know how to fix the information. Older adults made these comments when using the first five versions of the PMLHC, and after the twelfth participant who was an older adult, no further comments were coded for this subcategory.

Doesn't tell the whole story. Three (12.5%) older adults felt the PMLHC was too limited by only asking about their arthritis pain. They worried that the whole story was not being told because it was hard to put in the computer what really happened. One older adult expressed that she had trouble expressing nuances of her treatment outcomes because treatments might worsen symptoms before helping.

Difficulty remembering details. Seven (29.2%) older adults were concerned that their PMLHCs might not have accurate time frames because “that’s very difficult to go back and remember.” One (4%) older adult expressed that he did not think about the past and that made recalling information from years ago harder for him. Another older adult felt that most people overlooked details and could not think of the actual month that something occurred.

Missing features and suggestions for PMLHC development. Older adults contributed many suggestions for the development of the PMLHC that included pointing out missing features and suggesting ways the instrument could be altered. Table 8 contains a breakdown of the suggestions and missing features that were incorporated into PMLHC versions and that that were not included (see Table 8). Included comments involved needing to correct the available

date ranges (go back 50 years and up to present day), adding back buttons to allow answers to be changed, and adding the ability to skip beyond unnecessary rounds of treatments to the end of the instrument. Based on the suggestion of two (8.3%) older adults, a question was added to allow older adults to describe which body part each round of treatments described. Several older adults discussed that some of their pain treatments were missing (e.g., knee scope, gabapentin, and chiropractor) from the PMLHC list; therefore, a fill in the blank was added to the menu item called “other.” The introduction section was edited after one older adult suggested that the instrument should be prefaced with information about the concept of multiple rounds of treatments.

An additional seven comments from five (20.8%) different older adults covered a range of suggestions that either were outside the scope and concept of the PMLHC or were not currently possible due to technical requirements. These ideas included adding a place to describe adverse reactions to treatments, adding journal style entries for long-term use and re-use of the PMLHC, changing the wording of questions to clarify the long-term nature of the treatment rounds, and asking if onset of symptoms was sudden or gradual. Older adults also suggested that they might prefer to record date ranges (e.g., last 10 years and last 5 years), instead of having to record actual months and years of starting treatments. One (4%) older adult wanted to specify that one of her treatment choices (a brace) was used as a preventative measure. Finally, one (4%) older adult wished that she could have described her treatment results in greater detail to show that might treatments hurt her before helping.

Phase 2, Part 2: Pilot test for accuracy of PMLHCs. After 12 participants, saturation was reached on revision suggestions for the computerized PMLHC, and a small pilot test was conducted with the remaining participants using the enhanced interview technique. The

enhanced interviews added using the completed PMLHC opened on the screen, while the researcher and participant reviewed the information. In this way, participants could describe any missing information and discuss their responses. Twelve eligible enhanced interviews were included in this analysis. Four (33%) participants confirmed that their PMLHCs were accurate and had no omissions or errors. Eight (66%) participants revealed that their PMLHCs had errors. There were two anomalous entries noted and four types of errors found (omitted outcomes, recorded wrong choice [treatment or outcome], omitted treatments, and missing entire segments of their pain management history).

Anomalous entries. Two (16.7%) participants recorded outcomes that seemed incongruous with basic medical understanding of how treatments could affect patients. One participant recorded that pain interference with function increased when they used NSAIDs and glucosamine. The second participant recorded that pain interference with function increased when they used acetaminophen.

Omitted outcomes. For each treatment that a participant recorded, they were asked to choose the outcomes they experienced for both pain intensity (i.e., increased, decreased, and stayed the same) and for pain interference with function (i.e., increased, decreased, and stayed the same). Omitted outcomes were the most minor of the errors noted and were found in two (16.7%) participants' PMLHCs. One participant reported her PMLHC using four rounds with 33 recorded treatments and omitted two (6%) pain intensity outcomes and found (12%) pain interference with function outcomes. Another participant used five rounds to record her PMLHC with 11 recorded treatments and omitted one (9%) of the pain interference with function outcomes.

Recorded wrong choice. This type of error was found in two (16.7%) of the PMLHCs. The first error involved one participant who recorded NSAIDs as a treatment, but when interviewed, revealed that she only ever used acetaminophen. The second error occurred when one participant recorded both increased and decreased pain intensity with function for one treatment but only meant to enter increased.

Omitted treatments. Five (41.7%) participants accurately recorded their rounds of treatments but omitted individual treatments from one or more of those rounds. No pattern was found in the type of treatment omitted by participants. Three participants missed one treatment each (e.g., exercise, assistive device, and “gel shot”), and two participants missed multiple treatments. The first participant who missed reporting multiple treatments recorded four treatment rounds with 33 recorded treatments but failed to record the previous use of an assistive device and the current use of physical therapy. The second participant who missed several treatments recorded six treatment rounds with eight reported treatments. This participant failed to record the earliest cortisone injection that was tried, the use of “pain patches,” and use of opioids.

Missing entire segments of their pain management history. Three (25%) participants’ PMLHCs were missing entire segments of their pain management histories. When interviewed, these three participants were competent historians of their own pain management journey, which showed that recall of information was not the problem. One participant recorded three rounds of treatments but failed to enter the final and current treatment regimen. During the interview, the participant described a current treatment regimen that included exercise, NSAIDs, massage, and use of a topical agent. However, these four treatments were reported by the participant in an

earlier round of treatments, which would have allowed a researcher to identify overall treatments used, even though the timeline of treatments was incomplete.

A second participant with a long pain management history simplified answers on the PMLHC to reflect only two rounds of treatments and omitted many details, while blending other aspects of treatments together. The first PMLHC entry was recorded as Aug 2000 cortisone injections for hip pain (omitted back and knee pain). However, when interviewed, the participant explained that back pain was the first symptom experienced, and treatment began with cortisone injections in the back. After two sequential injections failed to help with pain, they were referred to an orthopedic doctor who diagnosed advanced knee arthritis and recommended bilateral total knee replacements. The second PMLHC entry (Dec 2000) was labeled as hip again and only listed total joint replacement as treatment. During the interview, the participant described how one knee was replaced in 2000; two years later, the second knee was replaced. Additional information missing from the PMLHC included two more rounds of surgeries for each total hip replacement (2006 and 2009) and their current treatment regimen of weight loss, acetaminophen, topical agent, and assistive device.

The third participant with missing segments of information only filled in one round of four treatments in the PMLHC and omitted the date. During the interview, the participant could recall four distinct rounds of treatments for different body parts with arthritis and could recall the years that major treatment changes occurred. The current treatment regimen of exercise, acetaminophen, positioning, chiropractor, and heat/cold were omitted from the PMLHC.

Development and accuracy of the PMLHC. For this project, the researcher crafted a LHC based, patient assessment instrument using a pre-existing quantitative software product (Qualtrics©). Using a pre-existing software product limited the types of edits that could be

achieved. Additionally, the Qualtrics© software did not support printout options based on individual questionnaires; instead, the software was designed to produce quantitative, aggregate data on how many people answered each question, each way.

Using both observations and Phase 2 participant data, the PMLHC was edited and refined multiple times. Edits to the PMLHC were twofold: Some were intended to help older adults navigate through the online instrument, and others were to improve the accuracy of the pain management history collected (see Table 9 for list of edits per PMLHC version). For example, as some early participants failed to notice they needed to mark outcomes in both the pain intensity and pain interference with function sections for each treatment, the two outcomes were separated into two different tables to help highlight the need for both types of outcomes.

To answer the second half of Research Question 2 (e.g., does the computerized PMLHC collect accurate pain management histories as compared to interview data?), the accuracy of the PMLHC was examined in two ways: through the evolution of Phase 2 data collection. The first method used the pain management life history calendar interview technique developed by McDonald and Barri (2015). Through these interviews, many discrepancies were noted in participants' pain management timelines that helped shape the edits for the PMLHC Versions 2 through 6 (e.g., back buttons were added because some participants expressed the need to change a previous answer). After the first nine interviews, an enhanced interview technique was developed. Enhanced interviews for the 12 pilot test participants involved having their PMLHC timelines open on screen and visible to them. In this way, participants were asked directly to confirm if their answers were accurate.

Phase 2, Part 3: Contents of pilot PMLHCs. Data collection for Phase 2 was amended to allow additional participants to test Research Question 3: Is the computerized PMLHC a

feasible pain management research instrument? The pilot participants successfully recorded pain management histories that included details about the types of treatments they tried, the outcomes they experienced, when they started or changed treatments, and what body parts were affected by osteoarthritis pain. Treatment types recorded by participants included (a) medical treatments (prescribed medications, physical therapy, and cortisone injections) and (b) complementary/alternative therapies (exercise, heat/cold, rest, positioning, chiropractic care, massage, yoga, tai chi, meditation, glucosamine, and topical agents). The data presented in this section represented the self-recorded information combined when necessary with interview obtained information to explore the contents of the PMLHCs of all 12 pilot participants.

Overall, 12 older adults in the pilot study could record many aspects of their pain management histories. Participants successfully recorded both pain intensity and pain interference with function outcomes for most of the treatments recorded (see Table 10). Earliest treatment histories recorded by participants ranged from one to 40 years prior ($M = 15.4$ years, $SD = 11.21$). Nine participants reported histories longer than seven years. Although some treatment regimens were simple (one treatment), other participants reported up to 11 different treatments in a round. Ten (83.3%) older adults recorded two or more treatment regimens (with a range of 1 to 6). Three participants recorded treatment histories that started with a few treatments and added more over time. However, six (50%) participants recorded treatments that started with one or a few treatments, which increased to many treatments, but then decreased the number of treatments in present treatment regimens. This treatment pattern was not associated with years of arthritis pain or types of treatments tried, discarded, or still used.

The pilot test results had four (33.3%) participants without errors and eight (66.7%) with errors of varying clinical significance. Participants recorded 123 treatments, with 245 outcomes

(combined pain intensity and pain interference with function) and seven outcomes (2.7% out of 252 minimum outcomes) left blank by participants (without data). Of the 25 outcomes recorded for both pain intensity and pain interference with functioning, 194 (79.2%) were positive outcomes; 10 (4.1%) entries were negative outcomes; and 41 (16.7%) entries were “no change.” Two (16.7%) participants recorded multiple outcomes for some of their treatments (e.g., cortisone injection was coded with pain intensity as “decreased” and “no change”). One participant recorded two outcome choices each for three treatments, and when interviewed, the participant described that the treatments helped for a time, and then became ineffective.

Table 11 shows some specific treatments reported by the older adults. Nine (75%) participants reported arthritis in their hips or knees, but only four (33%) participants reported having total joint surgery (two people had single joint replacements, and two people had multiple joint replacements). One (8%) participant reported arthritis in the hands; one (8%) reported back arthritis; and one (8%) reported multiple sites (e.g., neck, back, elbow, wrist, hands, shoulder, and ankles). No patterns were noted on rounds of treatments or individual treatments based on the body sites noted to have arthritis. Use of exercise as part of their current treatment regimens was reported by nine (75%) participants. Five (41.7%) participants reported the current use of NSAIDs; one (8.3%) participant stated he or she used no medication; and the remaining six (50%) reported use of acetaminophen. Each participant reported at least one pain treatment that helped lower their pain or decrease his or her pain interference with functioning. Complete PMLHC timelines for the 12 pilot participants are presented in Table 12.

Summary

Phase 1 focus group transcripts were evaluated and analyzed into three clusters that determined providers’ acceptance of the PMLHC output and the nonsupport for the feasibility of implementing Phase 3 in a clinical setting. Following the original research plan, the researcher

developed the PMLHC into a research instrument based on data from Phase 1. Phase 2 data were collected to develop the computerized PMLHC, and these showed older adults' suggestions for editing the PMLHC, opinions of older adults on the acceptability and feasibility of using the PMLHC, and the contents of 12 participants' PMLHCs that were cross checked with focused interviews to examine the validity of the pain management histories.

Chapter 5 will discuss the findings and implications for future work. These findings will show ways in which the data helped develop the PMLHC as a research instrument. Chapter 5 will conclude with a summary.

Chapter 5: Discussion

This chapter is divided into seven sections to facilitate the examination of the findings and significance of the study. The first section is an overview of the study. The next section will cover the discussion of the research questions for Phases 1 and 2. Next, there are discussions of the challenges for future versions of the PMLHC and the potential benefits from using the PMLHC. The fifth section will contain the limitations of the entire study. The sixth section addresses the implications for future research, and the final section provides the conclusion.

Overview and Purpose of the Study

The purpose of the study was to develop and test a computerized pain management life history calendar assessment instrument. A multiphase approach was used to aid in the design and testing of the instrument. In Phase 1, the providers were shown a mockup of a pain management time line (PMLHC output) that was based on a timeline generated from face-to-face interviews conducted by McDonald and Barri (2015). In Phase 2 of the research, older adults filled out computerized PMLHCs, and then were interviewed. Throughout Phase 2, the PMLHC was edited based on feedback from the participants and researcher observations and notes. The Phase 2 methodology was updated several times to allow for greater understanding of the pain management histories that older adults recorded. Finally, Phase 2 was extended to allow a pilot test that examined the accuracy of the pain management timelines recorded by older adults.

Findings for the Research Questions

Phase 1 was designed to explore the first research question: Is the output from the computerized PMLHC both a feasible and acceptable pain management instrument for use by primary care providers? Phase 1 data did not support the feasibility and acceptability of the PMLHC output in its existing format. Some providers suggested ways to edit and change the form (plus signs, grids, or tables) that required computer technology support that was not

available for the current study. Other providers simply did not like the form and offered feedback that the form was confusing, included too much information, and generated more questions than they were interested in asking about pain management histories. Therefore, the proposed Phase 3 clinical trial was considered inadvisable. According to the original research plan, the results from Phase 1 focused the remaining phases of the project on development and pilot testing the PMLHC for use as a research instrument.

Phase 2 explored the second research question: Is the computerized PMLHC a usable instrument for older adults and does the computerized PMLHC collect accurate pain management histories as compared to interview data? To help answer the first half of this research question regarding usability of the computerized PMLHC, older adults were observed by the researcher while filling out the instrument and then interviewed to gain their perspectives. Older adults (66.7%) responded favorably to the PMLHC, although a few participants mentioned that recording the cycles of treatment regimens were too repetitive. The participants who successfully completed a computerized PMLHC showed that the interface was usable by older adults (ages ranged from 65 to 92). The second half of Research Question 2 concerned the accuracy of the pain management information collected, as described in Chapter 4. The specific concerns regarding participants' PMLHC content accuracy will be discussed in a later section of this chapter.

Research Question 3 stated the following: Is the computerized PMLHC a feasible pain management research instrument? To answer this research question, the contents of the pilot participants' PMLHCs were examined. There were errors found in the contents of a majority of the participants; therefore, the data did not support the feasibility of the current version of the PMLHC as a research instrument. However, there were many insights gained about ways in

which to improve the PMLHC with custom programming, which indicated that the concept should be developed further. Additionally, several older adults described that using the PMLHC was a self-reflection activity that helped them appreciate all that they had been through. Therefore, the data showed support for the concept of the PMLHC for potential use as a pain management self-reflection intervention.

Challenges for Future Versions of the PMLHC

In the current study, providers and older adults shared insights on several issues that would need to be overcome for future versions of the PMLHC. Those issues included providers feeling rushed and overwhelmed by too much data and worrying over patient acceptance of and ability to fill out a computerized instrument. The types of errors seen in the pilot PMLHCs indicated the following possible problems: (a) technical limits existed in the current PMLHC; (b) some patients might not want to participate in self-generated health data instruments; and (c) some patients might not have the health literacy needed to accurately record their PMLHC.

In this study, providers expressed concern about limited time during office visits and their need for a version of the PMLHC that was simple and easy to interpret. Research showed that providers only get to spend about 33% of their work day seeing patients, with the remainder of their day consumed with dictation, charting, desk work, updating medication orders, insurance issues, and office management work (Sinsky et al., 2016). Researchers have found that providers only spend an average of 15 minutes with each patient during primary care office visits (Hirsch et al., 2017; Tai-Seale et al., 2017). Primary care providers need to balance the minutes of an office visit between multiple topics and patient questions (J. Robinson, Tate, & Heritage, 2016).

Providers in this study were hesitant to adopt a new patient assessment form that might generate more questions than they wanted to deal with and this finding was consistent with the literature. Research has shown that providers sometimes minimize or avoid discussing chronic

pain topics in primary care settings (Alami et al., 2011; Hill, Dziedzic, & Nio Ong, 2011; Paskins, Sanders, Croft, & Hassell, 2015; Thomas, Moore, Roddy, & Peat, 2013). Using videotaped office visits and post-consultation interviews with both providers and osteoarthritis patients, Paskins et al. (2015) showed that although providers thought they were asking pain management questions and follow-ups, they often did not ask these questions. They observed that general avoidance of the pain management topic also manifested when providers and patients minimized osteoarthritis pain as being “just part of getting old.” When asked why they did not focus on osteoarthritis pain management, providers expressed their preference was to focus on problems they could influence more, such as management of hypertension (Paskins et al., 2015). In two studies, patients described interactions with providers who minimized osteoarthritis as a disease, failed to assess the issue fully, and did not prescribe any treatments (Hill et al., 2011; Thomas et al., 2013). These findings were also consistent with the trialing to pain control theory, which demonstrated that providers might reach a point when they felt there were no more treatment options to offer (McDonald, 2014). In the present study, some providers expressed feeling overwhelmed by data and did not know how they would handle a full history of pain management information.

Providers expressed concerns that some older adults in their practices might never be able to take advantage of computerized instruments due to a lack of computer access, lack of computer skills, low health literacy, and language barriers. Smith et al. (2015) examined factors related to registration and use of a patient portal linked to an electronic health record. They found that gender, race, education level, and numbers of chronic conditions were associated with patient portal registration rates. Those most likely to register were either White (non-Hispanic), male, college educated, or had fewer chronic conditions. This finding was supported in the

current study: Most participants (91.6%) were White (non-Hispanic). Paradoxically, the literature showed that while some older adults struggled with computer skills, they were also the fastest growing demographic for online access and usage (Nielson, 2013).

Older adults' limited access to the Internet and unfamiliarity with computers may be a self-limiting problem because as Americans age, more of them will be familiar with computers and Internet use. Researchers have estimated computer and Internet usage at 79% to 90% for all U.S. adults (Ryan & Lewis, 2017; A. Smith, 2014). Additionally, 94.8% of households with members under age 18 have computers (Ryan & Lewis, 2017). The American Medical Informatics Association (2016) published a list of principles to help guide the industry to create a health care record environment that empowered patients with greater control of their personal health information. One of the key ideas was to reduce the burden of difficult interfaces with patient portals (American Medical Informatics Association, 2016). Irizarry et al. (2017) examined older adults' health literacy and attitudes toward using a patient portal and found that older adults liked the perceived value of having their information in one convenient place. They also found participants valued the possibility of communication with their providers through the portal (Irizarry et al., 2017). They suggested that computerized tools, such as patient portals, have the potential to improve older adults' engagement with their health care.

The errors in the PMLHC outputs might be due to the technical limitations of the PMLHC or to human factors. Some of the errors in the pilot PMLHCs were minor and could be the result of simple human mistakes (e.g., omitting an outcome or forgetting one treatment). These types of minor errors could be minimized with a customized PMLHC employing design intelligence features to remind participants if an answer is left blank. Additionally, the repetitive nature of the treatment rounds could be minimized if question flow was controlled by more

sophisticated programming logic that asked questions based on content chosen by the participant. A custom PMLHC could also display a visual representation of the timeline as each participant filled in information. Such a visual cue was consistent with LHC methodology and had been used to help aid recall, catch entry errors, and keep participants engaged in the survey (Belli et al., 2013; Glasner, van der Vaart, & Dijkstra, 2015).

Future versions of the PMLHC could be custom designed to minimize participant confusion and maximize time line content. Social science researchers and computer scientists have begun computerizing life history methodology by building computer intelligence into the time diaries (Arunachalam, 2016; Glasner et al., 2015; Kite, 2007; Kite & Soh, 2004), although only some of the work has been tested with participant-entered data. Glasner (2011) collaborated with a research software company (CentERpanel) to create a web-based calendar instrument to record life events of participants. Glasner et al. (2015) examined different styles of visual representations to determine what elements affected completion rates for their web-based life event survey. Kite and Soh (2004) worked to create a computer program with a specific type of database that would allow the future addition of a “survey assistant module” that could learn from previous entries, search for patterns, and then generate questions specific to each participant. Kite and Soh hoped the addition of the survey assistant module would enable the self-administration of complex life history calendar surveys. The work by these researchers represented the ground work for future applications of computerized, self-administered life history methodology, such as an improved and upgraded PMLHC.

The human factors that present challenges for future versions of the PMLHC include patient motivation and patient health literacy levels. When examining the data for evidence of the PMLHC’s usability, there were three participants who missed entire segments of their history

and had significant mistakes in their timelines. These participants used the computer independently, without appearing to have difficulties. Additionally, the interviews with all three participants revealed that they were good historians of their own pain management histories when questioned face-to-face. These findings indicate that the computerized PMLHC may not be a useable instrument for all patients. There may be some people who lack the motivation or the ability to fill out their own medical history accurately. However, older adults may be more engaged when the context is relevant to their immediate healthcare, rather than a research context.

When examining patient engagement with patient health portals or other aspects of their self-management, researchers have noted that some patients are either more inclined or more able to participate (Hibbard, Mahoney, Stockard, & Tusler, 2005). Hibbard et al. (2005) developed the Patient Activation Measure (PAM), a 13-item measure that scores patients' ability and confidence in handling their medical needs and communications. Having a reliable instrument that can measure patient readiness and ability to participate in their healthcare self-management has allowed researchers to begin to tailor interventions and treatments to meet the patients' abilities and willingness to engage (Hibbard & Greene, 2013). Future versions of the PMLHC should incorporate a screening, such as the PAM, to ensure the participants are good candidates for a patient generated health data instrument. To capture the widest possible demographic of older adults, researchers may need to provide assistance for some older adults either by offering computer assistance or an alternative data collection method, such as face-to-face interviews.

Health literacy skills may have contributed to the extensive errors found in the timelines of three (25%) of the participants. The errors found included missing entire regimens and

multiple surgical interventions. It was unclear if customizing the PMLHC would be enough to prevent this level of error. There might be a segment of the population of older adults who lacked the health literacy and computer skills to participate with patient generated health information in any format. Health literacy was defined by the Institute of Medicine as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (as cited in Nielsen-Bohlman, Panzer, & Kindig, 2004, p. 20). A future version of the computerized PMLHC might need to first test participants’ health literacy with an instrument like the Newest Vital Sign (NVS) test for health literacy (Weiss et al., 2005). The NVS is a 6-item assessment with questions about a nutrition label that is shown to participants (Weiss et al., 2005). This assessment could be used as a screening for participants or patients prior to having them attempt the PMLHC. Testing the PMLHC with a NVS score for each participant would add another dimension to examine the accuracy of the timelines. For example, future research could test the expectation that having a higher NVS score might be associated with more accurate medical history information on a PMLHC.

Potential Benefits of using the PMLHC

Trialing to pain control theory provides a framework for pain management that stresses the need for improved provider-patient communication and cooperation (McDonald, 2014). In the current study, both providers and patients discussed how using the PMLHC might help toward that goal. When asked to imagine the future version of the PMLHC in this study, providers expressed affirming views of the concept of having computerized, patient generated pain management histories. Providers looked forward to a future when patients could enter their pain management information, and an electronic alert within the electronic health record would

update the provider. Providers thought that the PMLHC would help patients become more engaged in their own care. One provider remarked, “It helps them be mindful of things, too like [sic] putting them in the process.” These opinions were consistent with an American Medical Association (2016) survey, in which providers discussed their requirements for adoption of electronic tools for their practices. Providers shared that they wanted electronic tools to be linked to electronic medical records, improve practice efficiency, be intuitive to use, and fit within their existing practice (American Medical Association, 2016).

In the current study, older adults offered many affirming comments about the PMLHC, saying it was thorough, offered a way to improve communication with providers, and helped them self-reflect on their pain management journey. Both older adults and providers noted that the PMLHC had the potential to help patients reflect on their pain management, be more engaged, and partner with providers in managing their chronic pain. Carman et al. (2013) defined patient engagement as patients, their families, and their representative and health professionals working in active partnership. The framework they developed showed the many factors that encompassed what patient engagement was and how it functioned (Carman et al., 2013). Carman et al.’s (2013) framework emphasized that patient engagement could occur on multiple levels from self-management activities (e.g., use of patient portal, mind-body exercise classes), to involvement with the healthcare system they were using (e.g., patient advisor on hospital committee), and on the health care policy level (e.g., work to change rules and regulations).

Patient-generated health data, such as the PMLHC, could be a concrete first step in activating patient engagement with their health care. In the future, patients who filled out a PMLHC could record their pain management medical history and goals into a linked electronic

medical record. The exercise of filling out the PMLHC would help patients self-reflect on their pain management and communicate information to their providers. For example, an older adult who filled out a PMLHC ahead of an office visit would provide their pain management history but would also demonstrate his or her willingness to be an active partner with the provider.

Researchers have examined the concept of patient engagement, which showed potential for outcome improvement across a variety of clinical situations (Grant et al., 2008; Sarkar et al., 2014; Tenforde, Nowacki, Jain, & Hickner, 2011; Toscos et al., 2016). Tenforde et al. (2011) reviewed patient involvement with web-based health portals for over 10,000 patients for 1 year. They found that the patients who used health portals ($N = 4036$) had favorable diabetes quality outcomes (lower A1c, lower blood pressure, and lower body mass index) compared to patients who did not use the health portals ($N = 6710$) after adjusting for patient demographics (age, socioeconomic status, gender and race). Sarkar et al. (2014) found greater medication adherence for patients who adopted the online prescription refill as their exclusive refill method. They showed that patients using the online prescription portion of their electronic medical record had decreased cholesterol levels and fewer gaps in taking their medications (after accounting for education level, health literacy, and English proficiency; Sarkar et al., 2014). These researchers demonstrated an association between patient engagement with electronic health records and improved outcomes.

In the current study, eight participants expressed that filling out the PMLHC helped them reflect on their treatment histories, think about what else they might try, and raised their awareness of their pain treatment journey. Researchers have described self-awareness related to physical health as the ways in which people compare how they used to function with how they currently function; moreover, it one includes considering past experiences and his or her desired

future experiences (Ghasemipour, Robinson, & Ghorbani, 2013). Self-awareness is a complex theoretical construct, and researchers have created instruments to study different components, such as mindfulness and integrated self-knowledge, and then compared these to mental and physical health measures (Ghasemipour et al., 2013; Sutton, 2016). Researchers have shown associations between greater mindfulness and integrated self-knowledge being present in people with stronger coping skills and better health status (McCracken & Velleman, 2010). The evidence was weak due to limitations in studies' designs and sizes, but these still showed an interesting direction for more investigation (Ghasemipour et al., 2013; McCracken & Velleman, 2010; Nordin, Michaelson, Eriksson, & Gard, 2017). Future research needs to be conducted to continue to test the relationships between self-awareness and health related outcomes in addition to ways to bolster and support self-awareness in patients. The self-administered, computerized PMLHC was designed to help chronic pain patients recall their entire pain management histories which is by definition a self-reflection activity.

The PMLHC has the potential for use as a self-awareness intervention for chronic pain patients. The following study demonstrates both the potential for computerizing LHC methodology, and implications that people may benefit from participation through improved self-awareness. Bay-Cheng, Maguin, and Bruns (2018) presented one example of an online, self-administered life history calendar. They adapted their sexual LHC interview protocol to a custom-made, self-administered, digital format (d/SLHC). Like the PMLHC, the d/SLHC produces a timeline with some quantitative data (dates of occurrences and experiences) and some qualitative data (sections for free text comments and areas for various media input, such as icons, video, and images). Bay-Cheng (2017) designed the d/SLHC to function in two ways (a) as a research instrument to understand sexual histories and (b) as an instrument of self-reflection that

might help bolster the sexual well-being of participants. Participants who used the d/SLHC reported that the experience was an emotional challenge that helped them understand themselves and their past relationships (Bay-Cheng, 2017). Similarly, the PMLHC shows the potential to function both as a research/assessment instrument and to engage patients with self-reflection.

Improved patient self-reflection supports patient involvement with Phases 2 and 3 of the trialing to pain control theory (McDonald, 2014). The self-reflective activities of filling out a PMLHC can provide a pain management history for providers and patients as a starting place to decide on the next course of treatments. McDonald theorized that revisiting discarded treatments may help decrease the impression that the patient is running out of treatment options. Using a patient's PMLHC, a provider can review previously tried treatments that may have been prematurely discarded as unhelpful when pain first started. Researchers have recommended revisiting previously discarded treatments and using these in correct dosages for correct lengths of time as a strategy for treating chronic pain patients (McDonald & Barri, 2014; Mills, Torrance, & Smith, 2016).

Additionally, the PMLHC self-reflective activities might be a possible intervention. Older adults in the current study commented that the action of filling out the PMLHC helped them think about when pain started and reflect on all the treatments that they tried. Miller-Matero, Chipungu, Martinez, Eshelman, and Eisenstein (2017) found that when chronic pain patients were not fully aware of the pain coping skills that they had been using, they were more likely to suffer from depression and anxiety. Although their work did not investigate why the effect was present, Miller-Matero et al. suggested that clinicians should help patients become more aware of their pain treatments and coping strategies to help lower depression rates.

Pain self-management content generated from the PMLHC. The PMLHC timelines created by the pilot participants can be examined in multiple ways, including patterns of pain management treatments, as well as types and numbers of treatments used. Examination of the patterns of pain treatments was limited due to the small pilot sample, but the PMLHC showed more treatment changes and different change-of-usage patterns than previous research has shown. When examining how often patients change treatments, Langley and Liedgens (2013) found that 70% of people with back pain did not change treatments after their initial diagnosis. McDonald and Barri (2015) found that older adults tended to add treatments over time.

In the current study, six of the participants started with a small number of treatments, added more treatments, but eventually trimmed down to fewer treatments. The length of time that participants reported treatment use was consistent with the literature. The current study relied on self-reported diagnosis of osteoarthritis, but findings were similar to a study of provider diagnosed back pain patients, where 56% of patients reported chronic back pain of six or more years duration (Langley & Liedgens, 2013).

In the current study, five participants noted using NSAIDs to help control pain, which goes against the recommendations that older adults should avoid long-term use of NSAIDs. Using NSAIDs is discouraged due to the higher potential for complications (e.g. gastrointestinal bleed; Marcum et al., 2014; McAlindon et al., 2014). Acetaminophen and exercise are among the top recommended osteoarthritis treatment modalities, as based on research (Abdulla et al., 2013; McAlindon et al., 2014). Many older adults in the current study reported the current use of exercise and or acetaminophen to help manage their osteoarthritis symptoms, although the PMLHC did not capture the types, frequency, or intensity of each persons' exercise. A future

version of the PMLHC could be designed to elicit details of exercise use by using drop down menus.

One older adult reported the current use of opioid medication. Opioid use for older adults with osteoarthritis has been rising along with overall opioid use in the general population (Steinman, Komaiko, Fung, & Ritchie, 2015). Researchers have linked opioid use with the older adult population to a possible higher risk of dementia (Dublin et al., 2015) and increased fall risk (Rolita, Spegman, Tang, & Cronstein, 2013). The first step in adopting evidence-based clinical recommendations requires an understanding of what patients are currently using to help control their pain. Providers and researchers both need to know what medications patients have used now and in the past, which the PMLHC can collect.

In the current study, complimentary/alternative therapies in combination with medical treatments were recorded by 11 (91.6%) participants. The exception was one older adult who exclusively used exercise as the only treatment. The high prevalence of combining modalities was similar or greater than previous research on complementary/alternative treatment use for various types of chronic pain patients. In a focus group study with 50 women with arthritis, all participants reported using combinations of traditional and alternative treatments for their pain (Cheung, Geisler, & Sunneberg, 2014).

In the present study, two older adults reported current use of glucosamine. Providers need to be aware of all treatments a patient is using to know the possible side effects or conflicts with other treatments (Cheung et al., 2014). Some complementary/alternative treatments lack research evidence of their efficacy (e.g., glucosamine), and providers must help patients make informed decisions regarding the cost versus value of trying some alternative therapies (Park, Hirz, Manotas, & Hooyman, 2013).

Cheung et al. (2014) found that the participants often used word of mouth recommendations from people they know, the Internet, and support groups when seeking complementary/alternative treatments and often did not tell their providers about the alternative treatment modalities they used. Jawahar, Yang, Eaton, McAlindon, and Lapane (2012) found that 51% of women and 41% of men used complementary/alternative treatments for their knee arthritis pain (note: they did not include exercise as a complementary treatment). Jawahar et al. (2012) reported that at least half of their participants used combinations of complementary/alternative treatments and traditional medications for pain. Mbizo, Okafor, Sutton, Burkhart, and Stone (2016) found complementary/alternative treatments were used by over 79% of patients suffering from chronic back pain, neck pain, and chronic or rheumatoid arthritis. The PMLHC captured complementary/alternative treatments but additional questions could be added to allow greater detail, such as asking if participants told their providers about these treatments.

Both providers and older adults contributed affirming evidence of the feasibility and acceptability of an improved, future version of the computerized PMLHC and its output form. Phase 1 providers contributed a variety of opinions that shaped the conclusion that providers were interested in the concept of the PMLHC, but they were not willing to use the current output format of the PMLHC. Providers and older adults recognized potential benefits of having patient-generated data to communicate pain management histories, but they identified many areas of concern that would need improvement and development prior to testing the PMLHC in either a research or clinical setting.

Limitations

The findings from this study should be interpreted cautiously because of the small numbers of participants. Phase 1 of this study was conducted at three locations of one, large

university-based practice, and two of the focus groups had fewer participants than recommended by Krueger and Casey (2015). Phase 1 participants lacked racial diversity as the attendees were primarily White, non-Hispanic medical doctors. Phase 2 participants were also primarily White, non-Hispanic women (only five men), and participation was limited to English speakers only.

When conducting the enhanced interviews, some of the participants might have downplayed any errors they saw in their PMLHC because they sought to give socially acceptable responses to the researcher. Participants might have wanted to “help” the researcher, similar to Orne’s (1962) proposed phenomenon of demand characteristics in social science. Orne’s model suggested that participants might guess the purpose of the research and then try to match their responses to what they perceive to be the desired responses (McCambridge, de Bruin, & Witton, 2012; McCambridge, Kypri, & Elbourne, 2014).

Another limitation of the study was that the instrument was designed and edited without formally trying to incorporate plain speech or reading level standards, although expert advice was used to choose content. Some of the observed errors were due to the reading level of instructions, section headings, and navigation aids. The computerized PMLHC was technically limited due to utilization of an existing questionnaire software (Qualtrics©) and by not having a computer scientist available for consultation. Using an existing software product limited the PMLHC display options and did not allow the output to be viewed in a visual display that might have helped older adults recall and correct their timelines.

When examining the PMLHC outcome results, patients’ recall of treatment outcomes might be subject to recall bias. Some researchers have found that patients tend to remember their pre-procedure functional conditions and pain as worse than these actually were (Aleem et al., 2016; Daoust et al., 2017). In both studies, patients were evaluated while they were living

through their painful situations (diagnosis and surgery for lumbar decompression and fusion, and presentation in an emergency department for minor traumatic injuries), and then they were asked to recreate their pain and disability assessment measures up to two years after the events (Aleem et al., 2016; Daoust et al., 2017). Life history methodology was chosen to help minimize recall bias, but future research should be done that compares PMLHC results to known information and outcomes. Accuracy of outcome recall is important when encouraging providers and patients to revisit previously discarded treatments, as suggested by the trialing to pain control theory (McDonald, 2014).

One of the limitations of developing a computerized pain management instrument was that even with custom programming, the PMLHC might not be universally accessible. Care would have to be taken with future clinical designs to ensure that patients who could not utilize a computer or the PMLHC would still be included in the potential benefits. Future research projects using the PMLHC would need to consider which participants were not represented in the findings due to language, computer skill, access to computers, health literacy, or other factors. Alternative methods would need to be considered for the pain management histories of people who could not participate with the computerized instrument. For example, use of a computer assisted telephone interview could support computer illiterate adults by having the interviewer enter the patient's pain self-management data into a PMLHC.

Implications for Future Research

The computerized PMLHC is a unique instrument that utilizes patient generated health data to build a pain management history of treatments and outcomes. Future work should continue to improve and test the computerized PMLHC as both an instrument and an intervention. The findings from this study will help craft a custom instrument that will aid patients' self-management of osteoarthritis pain. Self-management of pain will be supported

with the reflection and self-awareness that patients would use to fill in their PMLHC. Sections could be added that help users identify pain management goals. Future research should test if repeated use of the PMLHC helps users be mindful of improvements that they might have not have noticed.

The improved PMLHC should also be tested in a clinical setting for use with primary care providers. Strategic partnerships with electronic health record companies and computer scientists will be needed. Researchers should examine the pain topic communication stimulated when patients provide their self-recorded histories to their providers. Long-term studies are needed to examine the effects of improved communication and patient activation (using a PMLHC) on patients' pain management outcomes. Although developed with older adults with osteoarthritis, the PMLHC should be applicable for use with other types of chronic pain patients, such as those with chronic low back pain, fibromyalgia, and headaches.

A custom built PMLHC will include a visual timeline, branches of questioning that helped people describe their pain management histories without repetition, required fields to prevent missing data, and customized output (for electronic medical record inclusion or as print outs). Additional sections could be added to the PMLHC to allow pre-screening patients for health literacy, a goal-setting section, and a free text area for patients to record any thoughts or questions they have for their providers. Future versions of this work would need to incorporate guidelines for optimal reading level and health literacy considerations. A patient activation measure (Hibbard & Greene, 2013) could be added to help determine which patients could benefit from an online self-management program. Such screenings would allow researchers to examine how different types of patients record their pain management histories and use the results to determine what patient populations can benefit most from the computerized PMLHC.

The PMLHC can be adapted to work on portable devices, such as touch screen tablets and smart phones making the instrument portable and increasing availability. The PMLHC can be either an addition to existing pain self-management programs that are web-based applications or it as an addition to an electronic medical record. Either type of platform can offer links to activities and educational content based on the participants' answers and preferences. Reminders and inspirational content can be set up that text or alert users to help them stay motivated.

To enhance the PMLHC as a research instrument, the LHC methodology would easily facilitate the addition of more of a participant's life experiences to gain a greater understanding of their pain management history in context with work experiences, activity levels, recreational activities, hobbies, and sports involvement. For example, expanding the sections on exercise would capture more detailed information to assist researchers to examine types of exercises performed, and duration and intensity. Researchers and computer scientists could create customizable web-based PMLHC with interchangeable modules. The modules would allow a researcher to pick and choose timeline categories based on the elements being investigated for each specific project. As well as using the BPI-SF to measure pain intensity and pain interference with activity, added modules could include an assessment of the participants' baseline for activities of daily living, a quality of life measurement, and employment history. The research possibilities of an Internet-based, self-administered PMLHC with optional modules increases the pool of potential participants and offers extensive flexibility.

Conclusions

Researchers and clinicians struggle with determining the best ways to help patients with chronic pain achieve positive outcomes. The trialing to pain control theory is a general theory of pain management that contains recommendations for providers and patients on ways in which to work together to improve pain management outcomes (McDonald, 2014). As a clinical

instrument, the PMLHC has the potential to improve communication between providers and patients by helping patients pre-record their histories when they can reflect and remember details. The basic problem identified in the theory indicates that providers and patients can reach a point in chronic pain management when they feel they have no more options to try. The PMLHC was conceived to help providers and patients re-examine previous treatments and consider new combinations of previously unsuccessful options. Provider-patient relationships may benefit if patients demonstrate greater engagement with healthcare through self-reflection activities, such as the PMLHC.

The purpose of this study was to develop and test a computerized PMLHC. In Phase 1, providers examined a mock-up of a PMLHC output, and their input shaped the remainder of the project to focus on development and testing of the instrument for use as a research instrument. Providers rejected the output form but embraced the concept of the computerized PMLHC and offered suggestions, including embedding it in electronic health records. One of the key findings from the provider focus groups was their hope that a patient generated PMLHC might improve provider-patient communication and provider-patient relationships. An effective future version of the PMLHC would directly increase patient engagement and provide additional pain management history information for providers. For clinical applications, future versions of the PMLHC need to be developed with collaboration from primary care providers to ensure that usability and acceptability are achieved. The goals of an integrated PMLHC remain to improve provider-patient relationships and patient pain management outcomes. These goals may be achieved through improved communication, enhanced patient engagement, and the PMLHC as an additional asset for providers to utilize when helping patients trial to pain control.

Phase 2 helped establish the possibilities of using the computerized PMLHC as a research instrument. Usability and feasibility testing of the computerized PMLHC revealed some vulnerabilities both in the design of the instrument and with the limited computer skill sets of some older adults (both the ones who would not volunteer, and the three participants who were unable to independently complete the PMLHC). The question of the feasibility of older adults interfacing with and using computerized instruments should be a self-limiting problem because the computer skills of younger generations will carry over as they age. The usability and accuracy issues revealed in this study could be decreased or eliminated with the help of computer scientists and a customized PMLHC. Customization of the PMLHC would permit integration of intelligent computer design (help decrease repetitive sections), visual cues, and timelines to help recall and accuracy, additional prompts for missed information, as well as modular sections for additional data capture.

Findings from Phase 2 showed that older adults could remember and record their pain management histories, which supported the feasibility of continuing the development of the PMLHC. Older adults also reported that they found the activity of filling out a PMLHC helped them reflect on their pain management experiences. The self-reflection finding indicates that the PMLHC should be explored as a possible self-reflection intervention. Future researchers could examine pain treatment patterns compared to participants' gender, household income, type of employment, or geographical locations. Future research could incorporate longitudinal studies examining self-awareness, patient engagement, and outcomes of pain management goals. The research possibilities of an Internet-based, self-administered PMLHC with optional modules for additional research measures increases the pool of potential participants.

Results from the current research developed the groundwork for a way to improve older adults' communication of their pain management histories by combining LHC methodology, computerization, and patient-generated health data. The computerized PMLHC is a unique instrument that captures pain self-management strategy trajectories currently only available through lengthy interviews. With further development, the PMLHC has the potential to enhance communication about past pain management strategies and assist to identify more tailored pain treatment regimens.

References

- Abdulla, A., Adams, N., Bone, M., Elliott, A., Gaffin, J., Jones, D., ... Schofield, P. (2013). Guidance on the management of pain in older people. *Age and Ageing*, 42, i1-i57. doi:10.1093/ageing/afs200
- Alami, S., Boutron, I., Desjeux, D., Hirschhorn, M., Meric, G., Rannou, F., & Poiraudau, S. (2011). Patients' and practitioners' views of knee osteoarthritis and its management: A qualitative interview study. *PLoS ONE*, 6(5), 1-9. doi:10.1371/journal.pone.0019634
- Aleem, I., Duncan, J. S., Ahmed, A. M., Zarrabian, M., Eck, J. C., Rhee, J. M., ... Nassr, A. N. (2016). Do lumbar decompression and fusion patients recall their preoperative status? A cohort study of recall bias in patient-reported outcomes. *The Spine Journal*, 16(10), S370. doi:10.1016/j.spinee.2016.07.306
- American Medical Association. (2016). *Digital health study: Physicians' motivations and requirements for adopting digital clinical tools*. Retrieved from <https://www.ama-assn.org/sites/default/files/media-browser/specialty%20group/washington/ama-digital-health-report923.pdf>
- American Medical Informatics Association. (2016). *AMIA public policy principles and policy positions: 2016-2017 priorities*. Retrieved from https://www.amia.org/sites/default/files/AMIA_2016-17_Policy_Priorities-Positions_170829.pdf
- Anderson, M., & Perrin, A. (2016). *13% of Americans don't use the Internet. Who are they?* Retrieved from Pew Research Center <http://www.pewinternet.org/fact-sheet/Internet-broadband/>

Arsoniadis, E., Tambyraja, R., Khairat, S., Jahansouz, C., Scheppmann, D., Kwaan, M., ...

Melton, G. (2015). Characterizing patient-generated clinical data and associated implications for electronic health records. *MEDINFO 2015: eHealth-enabled Health, 1*, 158-162. doi:10.3233/978-1-61499-564-7-158

Arunachalam, H. (2016). *Towards building an intelligent integrated multimode time diary survey framework* (Master's thesis). Retrieved from DigitalCommons@University of Nebraska – Lincoln. (Order No. 106)

Baker, S., & Watson, B. (2015). How patients perceive their doctors' communication: Implications for patient willingness to communicate. *Journal of Language and Social Psychology, 34*(6), 621-639. doi:10.1177/0261927X15587015

Baumbauer, K., Starkweather, A., Guite, J., & Manworren, R. (2016). Managing chronic pain in special populations with emphasis on pediatric, geriatric, and drug abuser populations. *Medical Clinics of North America, 100*, 183-197. doi:10.1016/j.mcna.2015.08.013

Bay-Cheng, L. (2017). Seeing how far I've come: The impact of the digital sexual life history calendar on young adult research participants. *The Journal of Sex Research, 54*(3), 284-295. doi:10.1080/00224499.2016.1139033

Bay-Cheng, L., Maguin, E., & Bruns, A. (2018). Who wears the pants: The implications of gender and power for youth heterosexual relationships. *The Journal of Sex Research, 54*(1), 7-20. doi:10.1080/00224499.2016.1276881

Belli, R. (1998). The structure of autobiographical memory and the event history calendar: Potential improvements in the quality of retrospective reports in surveys. *Memory, 6*(4), 383-406. doi:10.1080/741942610

- Belli, R. (2000). Computerized event history calendar methods: Facilitating autobiographical recall. In *American statistical association proceedings of the section on survey research methods* (pp. 471-475). Alexandria, VA: American Statistical Association.
- Belli, R., Agrawal, S., & Bilgen, I. (2012). Health status and disability comparisons between CATI calendar and conventional questionnaire instruments. *Quality and Quantity Journal*, 46, 813-828. doi:10.1007/s11135-010-9415-8
- Belli, R., Bilgen, I., & Al Baghal, T. (2013). Memory, communications, and data quality in calendar interviews. *Public Opinion Quarterly*, 77, 194-219. doi:10.1093/poq/nfs099
- Belli, R., & Callegaro, M. (2009). The emergence of calendar interviewing: A theoretical and empirical rationale. In R. Belli, F. Stafford, & D. Alwin (Eds.), *Calendar and time diary: Methods in life course research* (pp. 31-52). Thousand Oaks, CA: Sage.
- Belli, R., Shay, W., & Stafford, F. (2001). Event history calendars and question list surveys: A direct comparison of interviewing methods. *Public Opinion Quarterly*, 65, 42-74. doi:10.1086/320037
- Benaroya, M., Elinson, R., & Zarnke, K. (2007). Patient-directed intelligent and interactive computer medial history-gathering systems: A utility and feasibility study in the emergency department. *International Journal of Medical Informatics*, 76, 283-288. doi:10.1016/j.ijmedinf.2006.01.006
- Berney, L., & Blane, D. (1997). Collecting retrospective data: Accuracy of recall after 50 years judged against historical records. *Social Science, & Medicine*, 45(10), 1519-1525. doi:10.1016/S0277-9536(97)00088-9

- Berney, L., & Blane, D., (2003). The lifegrid method of collecting retrospective information from people at older ages. *Research Policy and Planning*, 21(2), 13-21. Retrieved from <http://ssrg.org.uk/journal/>
- Bhattarai, P., Newton-John, R., & Phillips, J. (2017). Quality and usability of arthritic pain self-management apps for older adults: A systematic review. *Pain Medicine*, 0, 1-14. doi:10.1093/pm/pnx090
- Blane, D. (1996). Collecting retrospective data: development of a reliable method and a pilot study of its use. *Social Science & Medicine*, 42(5), 751-757. doi:10.1016/0277-9536(95)00340-1
- Brahmandam, S., Holland, W., Mangipudi, S., Braz, V., Medlin, R., Hunold, K., ... Platts-Mills, T. (2016). Willingness and ability of older adults in the emergency department to provide clinical information using a tablet computer. *Journal of the American Geriatrics Society*, 64, 2362-2367. doi:10.1111/jgs.14366
- Bren, L. (2006). The importance of patient-reported outcomes... it's all about the patients. *FDA Consumer*, 40, 26-32. Retrieved from <https://permanent.access.gpo.gov/lps1609/www.fda.gov/fdac/fdacindex.html>
- Brown, J., Swartzendruber, A., & DiClemente, R. (2013). Application of audio computer-assisted self-interviews to collect self-reported health data: An overview. *Caries Research*, 47, 40-55. doi:10.1159/000351827
- Carman, K., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223-231. doi:10.1377/hlthaff.2012.1133

- Cheung, C., Geisler, C., & Sunneberg, J. (2014). Complementary/alternative medicine use for arthritis by older women of urban-rural settings. *Journal of the American Association of Nurse Practitioners*, 26, 273-280. doi:10.1002/2327-6924.12063
- Chrischilles, E., Hourcade, J., Doucette, W., Eichmann, D., Gryzlak, B., Lorentzen, R., ... Levy, B. (2014). Personal health records: A randomized trial of effects on elder medication safety. *Journal of American Medical Informatics Association*, 21, 679-686. doi:10.1136/amiajnl-2013-002284
- Clarke, A., Martin, D., Jones, D., Schofield, P., Anthony, G., McNamee, P., ... Smith, B. (2014). "I try and smile, I try and be cheery, I try not to be pushy. I try to say 'I'm here for help' but I leave feeling... worried": A qualitative study of perceptions of interaction with health professionals by community based older adults with chronic pain. *PLoS ONE*, 9(9). doi:10.1371/journal.pone.0105450
- Cleeland, C. S. (2009). *The Brief Pain Inventory: User guide*. Houston, TX: The University of Texas M. D. Anderson Cancer Center.
- Daoust, R., Sirois, M. J., Lee, J. S., Perry, J. J., Griffith, L. E., Worster, A., ... & Émond, M. (2017). Painful memories: Reliability of pain intensity recall at 3 months in senior patients. *Pain Research and Management*, 2017, 1-7. doi:10.1155/2017/5983721
- Dawson, J., Thorogood, M., Marks, S., Juszczak, E., Dodd, C., Lavis, G., & Fitzpatrick, R. (2002). The prevalence of foot problems in older women: A cause for concern. *Journal of Public Health Medicine*, 24(2), 77-84. doi:10.1093/pubmed/24.2.77
- Dublin, S., Walker, R., Gray, S., Hubbard, R., Anderson, M., Yu, O., ... Larson, E. (2015). Prescription opioids and risk of dementia or cognitive decline: A prospective cohort study. *Journal of the American Geriatrics Society*, 63, 1519-1526. doi:10.1111/jgs.13562

- Elwyn, G., Pickles, T., Edwards, A., Kinsey, K., Brain, K., Newcombe, R., ... Wood, F. (2016). Supporting shared decision making using an option grid for osteoarthritis of the knee in an interface musculoskeletal clinic: A stepped wedge trial. *Patient Education and Counseling*, 99, 571-577. doi:10.1016/j.pec.2015.10.011
- Engel, L., Keifer, M., Thompson, M., & Zahm, S. (2001). Test-retest reliability of an icon/calendar-based questionnaire used to assess occupational history. *American Journal of Industrial Medicine*, 40, 512-522. doi:10.1002/ajim.1119
- Farzadnia, S., & Giles, H. (2015). Patient-provider health interactions: A communication accommodation theory perspective. *International Journal of Society, Culture & Language*, 3(2), 17-34. Retrieved from <http://www.ij scl.net/>
- Fisher, J., Ballantyne, P., & Hawker, G. (2012). Older adults living with osteoarthritis: Examining the relationship of age and gender to medicine use. *Canadian Journal on Aging*, 31(3), 323-333.
- Fitzcharles, M., Lussier, D., & Shir, Y. (2010). Management of chronic arthritis pain in the elderly. *Drugs and Aging*, 27(6), 471-490. doi:10.2165/11536530-000000000-00000
- Freedman, D., Thornton, A., Camburn, D., Alwin, D., & Young-DeMarco, L. (1988). The life history calendar: A technique for collecting retrospective data. *Sociological Methodology*, 18, 37-68. doi:10.2307/271044
- Gammons, V., & Caswell, G. (2014). Older people and barriers to self-reporting of chronic pain. *The British Journal of Nursing*, 23(5), 274-278. doi:10.12968/bjon.2014.23.5.274
- Gaskin, D., & Richard, P. (2012). The economic cost of pain in the United States. *The Journal of Pain*, 13(8), 715-724. doi:10.1016/j.jpain.2012.03.009

- Geller, J. (1999). Rural primary care providers' perceptions of their roles in the provision of mental health services: Voices from the plains. *The Journal of Rural Health, 15*(3), 326-334. doi:10.1111/j.1748-0361.1999.tb00754.x
- Ghasemipour, Y., Robinson, J., & Ghorbani, N. (2013). Mindfulness and integrative self-knowledge: Relationships with health-related variables. *International Journal of Psychology, 48*(6), 1030-1037. doi:10.1080/00207594.2013.763948
- Giles, H. (Ed.). (2016). *Communication accommodation theory: Negotiating personal relationships and social identities across contexts*. England: Cambridge University Press.
- Giles, H., & Ogay, T. (2006). Communication accommodation theory. In B. Whaley & W. Samter (Eds.), *Explaining communication: Contemporary theories and exemplars* (pp. 293-310). Mahwah, NJ: Erlbaum.
- Glaser, B. (1978). *Theoretical sensitivity*. San Francisco, CA: Sociology Press.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Aldine.
- Glasner, T. (2011). *Reconstructing event histories in standardized survey research: Cognitive mechanisms and aided recall techniques* (Doctoral dissertation). Retrieved from Researchgate.net. (254826281)
- Glasner, T., & van der Vaart, W. (2009). Applications of calendar instruments in social surveys: A review. *Quality and Quantity Journal, 43*, 333-349. doi:10.1007/s11135-007-9129-8
- Glasner, T., van der Vaart, W., & Belli, R. (2012). Calendar interviewing and the use of landmark events – implications for cross-cultural surveys. *Bulletin de Methodologie Sociologique, 115*, 45-52. doi:10.1177/0759106312445701

- Glasner, T., van der Vaart, W., & Dijkstra, W. (2015). Calendar instruments in retrospective web surveys. *Field Methods*, 27(3), 265-283. doi:10.1177/1525822X14554882
- Gogovor, A., Visca, R., Auger, C., Bouvrette-Leblanc, L., Symeonidis, I., Poissant, L., ... Ahmed, S. (2017). Informing the development of an Internet-based chronic pain self-management program. *International Journal of Medical Informatics*, 97, 109-119. doi:10.1016/j.ijmedinf.2016.10.005
- Gordon, K., Rice, H., Allcock, N., Bell, P., Dunbar, M., Gilbert, S., & Wallace, H. (2016). Barriers to self-management of chronic pain in primary care: A qualitative focus group study. *British Journal of General Practice*, 1, e209-e217. doi:10.3399/bjgp17X688825
- Grant, R., Wald, J., Schnipper, J., Gandhi, T., Poon, E., Orav, J., ... Middleton, B. (2008). Practice-linked online personal health records for Type 2 diabetes mellitus. *Archives of Internal Medicine*, 168, 1776-1782. doi:10.1001/archinte.168.16.1776
- Gudzune, K., Clark, J., Appel, L., & Bennett, W. (2012). Primary care providers' communication with patients during weight counseling: A focus group study. *Patient Education and Counseling*, 89, 152-157. doi:10.1016/j.pec.2012.06.033
- Haskard-Zolnieriek, K. (2011). Communication about patient pain in primary care: Development of the physician-patient communication about pain scale (PCAP). *Patient Education and Counseling*, 86, 33-40. doi:10.1016/j.pec.2011.03.020
- Hehl, J., & McDonald, D. (2014). Older adults' pain communication during ambulatory medical visits: An exploration of communication accommodation theory. *Pain Management Nursing*, 15(2), 466-473. doi:10.1016/j.pmn.2012.03.007

- Herrick, D., Nakhasi, A., Nelson, B., Rice, S., Abbott, P., Tehrani, S., ... Newman-Toker, D. (2013). Usability characteristics of self-administered computer-assisted interviewing in the emergency department. *Applied Clinical Informatics*, 4, 276-292. doi:10.4338/ACI-2012-09-RA-0034
- Hibbard, J., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs*, 32(2), 207-213. doi:10.1377/hlthaff.2012.1061
- Hibbard, J., Mahoney, E., Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the Patient Activation Measure. *Health Services Research*, 40(6), 1918-1930. doi:10.1111/j.1475-6773.2005.00438.x
- Hill, S., Dziedzic, K. S., & Nio Ong, B. (2011). Patients' perceptions of the treatment and management of hand osteoarthritis: A focus group enquiry. *Disability and Rehabilitation*, 33(19-20), 1866-1872. doi:10.3109/09638288.2010.550381
- Hincapie, A., Warholak, T., Murcko, A., Slack, M., & Malone, D. (2011). Physicians' opinions of a health information exchange. *Journal of the American Medical Informatics Association*, 18, 60-65. doi:10.1136/jamia.2010.006502
- Hirsch, A., Jones, J., Lerch, V., Tang, X., Berger, A., Clark, D., ... Stewart, W. (2017). The electronic health record audit file: The patient is waiting. *Journal of the American Medical Informatics Association*, 24(e1), e28-e34. doi:10.1093/jamia/ocw088
- Hochberg, M., Altman, B., April, K., Benkhalti, M., Guyatt, G., McGowan, J., ... Tugwell, P. (2012). American College of Rheumatology 2012 recommendations for the use of nonpharmacologic and pharmacologic therapies in osteoarthritis of the hand, hip, and knee. *Arthritis Care & Research*, 64(4), 465-474. doi:10.1002/acr.21596

- Holley, C., & Lee, P. (2010). Primary care provider views of the current referral-to-eye-care process: Focus group results. *Investigative Ophthalmology and Visual Science*, 51(4), 1866-1872. doi:10.1167/iovs.09-4512
- Institute of Medicine. (2011). *Relieving pain in America: A blueprint for transforming prevention, care, education, and research*. Washington, DC: National Academies Press. doi:10.17226/13172
- Irizarry, T., Shoemaker, J., Nilsen, M., Czaja, S., Beach, S., & Dabbs, A. (2017). Patient portals as a tool for health care engagement: A mixed-method study of older adults with varying levels of health literacy and prior patient portal use. *Journal of Medical Internet Research*, 19(3), e99. doi:10.2196/jmir.7099
- Jawahar, R., Yang, S., Eaton, C., McAlindon, T., & Lapane, K. (2012). Gender-specific correlates of complementary and alternative medicine use for knee osteoarthritis. *Journal of Women's Health*, 21(10), 1091-1099. doi:10.1089/jwh.2011.3434
- Kalso, E., Edwards, J., Moore, A., & McQuay, H. (2004). Opioids in chronic non-cancer pain: Systematic review of efficacy and safety. *Pain*, 112, 372-380. doi:10.1016/j.pain.2004.09.019
- Kapstad, H., Rokne, B., & Stavern, K. (2010). Psychometric properties of the brief pain inventory among patients with osteoarthritis undergoing total hip replacement surgery. *Health and Quality of Life Outcomes*, 8, 148. doi:10.1186/1477-7525-8-148
- Kennedy, J., Roll, J., Schraudner, T., Murphy, S., & McPherson, S. (2014). Prevalence of persistent pain in the U.S. adult population: New data from the 2010 National Health Interview Survey. *The Journal of Pain*, 15(10), 979-984. doi:10.1016/j.jpain.2014.05.009

- Keogh, E., Rosser, B., & Eccleston, C. (2010). e-Health and chronic pain management: Current status and developments. *Pain, 151*, 18-21. doi:10.1016/j.pain.2010.07.014
- Kim, E., Stolyar, A., Lober, W., Herbaugh, A., Shinstrom, S., Zierler, B., ... Kim, Y. (2009). Challenges to using an electronic personal health record by a low-income elderly population. *Journal of Medical Internet Research, 11*(4), e44. doi: 10.2196/jmir.1256
- Kite, J. (2007). *A flexible framework for knowledge engineering and automation of an adaptive conversational case-retrieval system* (Master's thesis). University of Nebraska, Lincoln. Retrieved from personal communication with author March 20, 2017.
- Kite, J., & Soh, L. (2004). *An online survey framework using the life events calendar* (Technical report). Retrieved from Digitalcommons@university of Nebraska – Lincoln. (Order No. 104)
- Kogan, A., Wilber, K., & Mosqueda, L. (2016). Person-centered care for older adults with chronic condition and functional impairment: A systematic literature review. *Journal of the American Geriatrics Society, 64*, e1-e7. doi:10.1111/jgs.13873
- Krippendorff, K. (2013). *Content analysis: An introduction to its methodology* (3rd ed.). Thousand Oaks, CA: Sage.
- Krueger, R., & Casey, M. (2015). *Focus groups: A practical guide for applied research* (5th ed). Thousand Oaks, CA: Sage.
- Langley, P., & Liedgens, H. (2013). Time since diagnosis, treatment pathways and current pain status: A retrospective assessment in a back pain population. *Journal of Medical Economics, 16*(5), 701-709. doi:10.3111/13696998.2013.777346

- Lapane, K., Quilliam, B., Benson, C., Chow, W., & Kim, M. (2014). One, two, or three? Constructs of the brief pain inventory among patients with non-cancer pain in the outpatient setting. *Journal of Pain and Symptom Management*, 47(2), 325-333. doi:10.1016/j.jpainsymman.2013.03.023
- Lobach, D. F., Silvey, G. M., Willis, J. M., Kooy, K. R., Kawamoto, K., Anstrom, K. J., ... Johnson, F. (2008). Coupling direct collection of health risk information from patients through kiosks with decision support for proactive care management. In *American Medical Informatics Association annual symposium proceedings* (Vol. 2008, p. 429). San Francisco, CA: American Medical Informatics Association.
- Luke, N., Xu, H., Mberu, B., & Goldberg, R. (2012). Migration experience and premarital sexual initiation in urban Kenya: An event history analysis. *Studies in Family Planning*, 43(2), 115-126. doi:10.1111/j.1728-4465.2012.00309.x
- MacDonald, K., Sanmartin, C., Langlois, K., & Marshall, D. (2014). Symptom onset, diagnosis and management of osteoarthritis. *Health Reports*, 25(9), 10-17. Retrieved from <https://www.statcan.gc.ca/eng/start>
- Makris, U., Agrams, R., Gurland, B., & Reid, C. (2014). Management of persistent pain in the older adult patient: A clinical review. *Journal of the American Medical Association*, 312(8), 825-836. doi:10.1001/jama.2014.9405
- Marcum, Z., Hanlon, J., Strotmeyer, E., Newman, A., Shorr, R., Simonsick, E., ... Perara, S. (2014). Gastroprotective agent underuse in high-risk older daily nonsteroidal anti-inflammatory drug users over time. *Journal of the American Geriatrics Society*, 62, 1923-1927. doi:10.1111/jgs.13066

- Martyn, K., & Belli, R. (2002). Retrospective data collection using event history calendars. *Nursing Research*, 51(4), 270-274. Retrieved from <https://journals.lww.com/nursingresearchonline/pages/default.aspx>
- Mbizo, J., Okafor, A., Sutton, M., Burkhart, E., & Stone, L. (2016). Complementary and alternative medicine use by normal weight, overweight, and obese patients with arthritis and other musculoskeletal diseases. *The Journal of Alternative and Complementary Medicine*, 22(3), 227-236. doi:10.1089/acm.2014.0390
- McAlearney, A., Schweikhart, S., & Medow, M. (2004). Doctors' experience with handheld computers in clinical practice: A qualitative study. *British Medical Journal*, 328, 1-5. doi:10.1136/bmj.328.7449.1162
- McAlindon, T. E., Bannuru, R., Sullivan, M. C., Arden, N. K., Berenbaum, F., Bierma-Zeinstra, S. M., ... Kwoh, K. (2014). OARSI guidelines for the non-surgical management of knee osteoarthritis. *Osteoarthritis and Cartilage*, 22(3), 363-388. doi:10.1016/j.joca.2014.01.003
- McCambridge, J., de Bruin, M., & Witton, J. (2012). The effects of demand characteristics on research participant behaviors in non-laboratory settings: A systematic review. *PLoS One*, 7(6), 1-6. doi:10.1371/journal.pone.39116
- McCambridge, J., Kypri, K., & Elbourne, D. (2014). Research participation effects: A skeleton in the methodological cupboard. *Journal of Clinical Epidemiology*, 67, 845-849. doi:10.1016/j.jclinepi.2014.03.002
- McCracken, L., & Velleman, S. (2010). Psychological flexibility in adults with chronic pain: A study of acceptance, mindfulness, and values-based action in primary care. *Pain*, 148, 141-147. doi:10.1016/j.pain.2009.10.034

- McDonald, D. (2014). Trialing to pain control: A grounded theory. *Research in Nursing & Health*, 37, 107-116. doi:10.1002/nur.21584
- McDonald, D., & Barri, C. (2015). The pain management life history calendar: a pilot study. *Pain Management Nursing*, 16(4), 587-594. doi:10.1016/j.pmn.2014.11.002
- McDonald, D., Shea, M., Rose, L., & Fedo, J. (2009). The effect of pain question phrasing on older adult pain information. *Journal of Pain and Symptom Management*, 37(6), 1050-1060. doi:10.1016/j.jpainsymman.2008.06.008
- McNeely, C., Barber, B., Spellings, C., Belli, R., Giacaman, R., Arafat, C., ... Mallouh, A. (2015). Political imprisonment and adult functioning: A life event history analysis of Palestinians. *Journal of Traumatic Stress*, 28, 223-231. doi:10.1002/jts.22015
- Mendoza, T., Mayne, T., Rublee, D., & Cleeland, C. (2006). Reliability and validity of a modified brief pain inventory short form in patients with osteoarthritis. *European Journal of Pain*, 10, 353-361. doi:10.1016/j.ejpain.2005.06.002
- Mian, A., & Scott, A. (2015). Treat to target in managing inflammatory arthritis. *British Journal of Hospital Medicine*, 76(1), 31-34. doi:10.12968/hmed.2015.76.1.31
- Miller-Matero, L., Chipungu, K., Martinez, S., Eshelman, A., & Eisentein, D. (2017). How do I cope with pain? Let me count the ways: Awareness of pain coping behaviors and relationships with depression and anxiety. *Psychology, Health & Medicine*, 22(1), 19-27. doi:10.1080/13548506.2016.1191659
- Mills, S., Torrance, N., & Smith, B. (2016). Identification and management of chronic pain in primary care: A review. *Current Psychiatry Reports*, 18, 22. doi:10.1007/s11920-015-0659-9

- Nahin, R. (2015). Estimates of pain prevalence and severity in adults: United States, 2012. *The Journal of Pain*, 16(8), 769-780. doi:10.1016/j.jpain.2015.05.002
- Neisser, U. (1986). Nested structure in autobiographical memory. In D. Rubin (Ed.), *Autobiographical memory* (pp. 71-81). England: Cambridge University Press.
- Neisser, U. (1997). The ecological study of memory. *Philosophical Transactions of the Royal Society B*, 352, 1697-1701. doi:10.1098/rstb.1997.0151
- Nico, M. (2016). Bringing life “back into life course research”: Using the life grid as a research instrument for qualitative data collection and analysis. *Quality and Quantity Journal*, 50, 2107-2120. doi:10.1007/s11135-015-0253-6
- Nielsen, J. (2013). Seniors as web users. *Nielsen Norman Group Website*. Retrieved from <http://www.nngroup.com/articles/usability-for-senior-citizens/>
- Nielsen-Bohlman, L., Panzer, A., & Kindig, D. (Eds.). (2004). *Health literacy a prescription to end confusion*. Washington, DC: The National Academies Press.
- Nordin, C., Michaelson, P., Eriksson, M., & Gard, G. (2017). It’s about me: Patients’ experiences of patient participation the web behavior change program for activity in combination with multimodal pain rehabilitation. *Journal of Medical Internet Research*, 19(1), e22. doi:10.2196/jmir.5970
- Orne, M. T. (1962). On the social psychology of the psychological experiment: With particular reference to demand characteristics and their implications. *American Psychologist*, 17(11), 776-783. doi:10.1037/h0043424
- Park, J., Hirz, C., Manotas, K., & Hooyman, N. (2013). Nonpharmacological pain management by ethnically diverse older adults with chronic pain: Barriers and facilitators. *Journal of Gerontological Social Work*, 56, 487-508. doi:10.1080/01634372.2013.808725

- Parlar, S., Fadiloglu, C., Argon, G., Tokem, Y., & Keser, G. (2013). The effects of self-pain management on the intensity of pain and pain management methods in arthritic patients. *Pain Management Nursing*, 14(3), 133-142. doi:10.1016/j.pmn.2010.08.002
- Paskins, Z., Sanders, T., Croft, P. R., & Hassell, A. B. (2015). The identity crisis of osteoarthritis in general practice: A qualitative study using video-stimulated recall. *The Annals of Family Medicine*, 13(6), 537-544. doi:10.1370/afm.1866
- Peat, G., Thomas, E., Wilkie, R., & Croft, P. (2009). Multiple joint pain and lower extremity disability in middle and old age. *Disability and Rehabilitation*, 28(24), 1543-1549. doi:10.1080/09638280600646250
- Persons, O. (2009). Pharmacological management of persistent pain in older persons. *Journal of the American Geriatrics Society*, 57, 1331-1346. doi:10.1111/j.1532-5415.2009.02376.x
- Ricks, T., & Harrison, T. (2011). Issues using the life history calendar in disability research. *Disability and Health Journal*, 4, 262-270. doi:10.1016/j.dhjo.2011.05.004
- Robinson, J., Tate, A., & Heritage, J. (2016). Agenda-setting revisited: When and how do primary-care physicians solicit patients' additional concerns? *Patient Education and Counseling*, 99, 718-723. doi:10.1016/j.pec.2015.12.009
- Robinson, K., Bergeron, C., Mingo, C., Meng, L., Ahn, S., Towne, S., ... Smith, M. (2017). Factors associated with pain frequency among adults with chronic conditions. *Journal of Pain and Symptom Management*, 54(5), 619-627. doi:10.1016/j.jpainsymman.2017.07.043
- Rolita, L., Spegman, A., Tang, X., & Cronstein, B. (2013). Greater number of narcotic analgesic prescriptions for osteoarthritis is associated with falls and fractures in elderly adults. *Journal of the American Geriatrics Society*, 61, 335-340. doi:10.1111/jgs.12148

- Ruland, C., Holte, H., Roislien, J., Heaven, C., Hamilton, G., Kristiansen, J., ... Ellison, M. (2010). Effects of a computer-supported interactive tailored patient assessment tool on patient care, symptom distress, and patients' need for symptom management support: A randomized clinical trial. *Journal of the American Informatics Association*, 17, 103-410. doi:10.1136/jamia.2010.005660
- Ryan, C., & Lewis, J. (2017). *Computer and Internet use in the United States: 2015*. Washington, DC: U.S. Department of Commerce, U.S. Census Bureau.
- Sanger, P., Hartzler, A., Lober, W. B., Evans, H. L., & Pratt, W. (2014). Design considerations for post-acute care mHealth: Patient perspectives. In *American Medical Informatics Association annual symposium proceedings* (Vol. 2014, p. 1920). San Francisco, CA: American Medical Informatics Association.
- Sanger, P., Hartzler, A., Lordon, R., Armstrong, C., Lober, W., Evans, H., & Pratt, W. (2016). A patient-centered system in a provider-centered world: Challenges of incorporating post-discharge wound data into practice. *Journal of the American Medical Association*, 23, 514-525. doi:10.1093/jamia/ocv183
- Sarkar, U., Lyles, C., Parker, M., Allen, J., Nguyen, R., Moffet, H., ... Karter, A. (2014). Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system. *Medical Care*, 52(3), 194-201. doi:10.1097/MLR.0000000000000069
- Schnipper, J., Gandhi, T., Wald, J., Grant, R., Poon, E., Volk, L., ... Middleton, B. (2012). Effects of an online personal health record on medication accuracy and safety: A cluster-randomized trial. *Journal of the American Medical Informatics Association*, 19, 728-734. doi:10.1136/amiajnl-2011-000723

- Shapiro, M., Johnston, D., Wald, J., & Mon, D. (2012). *Patient-generated health data* (White Paper). Research Triangle Park, NC: RTI International.
- Shields, C., Finley, M., Elias, C., Coker, C., Griggs, J., Fiscella, K., & Epstein, R. (2013). Pain assessment: The roles of physician certainty and curiosity. *Health Communications*, 28, 740-746. doi:10.1080/10410236.2012.715380
- Simsek, I., Simsek, T., Yumin, E., Sertel, M., Ozturk, A., & Yumin, M. (2010). The effects of pain on health-related quality of life and satisfaction with life in older adults. *Topics in Geriatric Rehabilitation*, 26(4), 361-367. doi:10.1097/TGR.0b013e3181fcdc11
- Sinsky, C., Colligan, L., Li, L., Prgomet, M., Reynolds, S., Goeders, L., ... Blike, G. (2016). Allocation of physician time in ambulatory practice: A time and motion study in four specialties. *Annals of Internal Medicine*, 165, 753-760. Retrieved from <http://annals.org/aim>
- Smith, A. (2014). *Older adults and technology use*. Retrieved from Pew Research Center <http://pewinternet.org/2014/04/03/older-adults-and-technology-use/>
- Smith, S., O'Connor, R., Aitken, W., Curtis, L., Wolf, M., & Goel, M. (2015). Disparities in registration and use of an online patient portal among older adults: Findings from the LitCog cohort. *Journal of the American Medical Informatics Association*, 22, 888-895. doi:10.1093/jamia/ocv025
- Steinman, M., Komaiko, K., Fung, K., & Ritchie, C. (2015). Use of opioids and other analgesics by older adults in the United States, 1999-2010. *Pain Medicine*, 16, 319-327. doi:10.1111/pme.12613

- Sutton, A. (2016). Measuring the effects of self-awareness: Construction of the self-awareness outcomes questionnaire. *Europe's Journal of Psychology*, 12(4), 645-658.
doi:10.5964/ejop.v12i4.1178
- Tai-Seale, M., Olson, C., Li, J., Chan, A., Morikawa, C., Durbin, M., ... Luft, H. (2017). The practice of medicine: Electronic health record logs indicate that physicians still split time evenly between seeing patients and desktop medicine. *Health Affairs*, 36(4), 655-662.
doi:10.1377/hlthaff.2016.0811
- Tenforde, M., Nowacki, A., Jain, A., & Hickner, J. (2012). The association between personal health record use and diabetes quality measures. *The Journal of General Internal Medicine*, 27(4), 420-424. doi:10.1007/s11606-011-1889-0
- Thielke, S., Sale, J., & Reid, C. (2012). Aging, are these 4 pain myths complicating care? *The Journal of Family Practice*, 61(11), 666-670. Retrieved from
<https://www.mdedge.com/jfponline>
- Thomas, M. J., Moore, A., Roddy, E., & Peat, G. (2013). "Somebody to say 'come on we can sort this'": A qualitative study of primary care consultation among older adults with symptomatic foot osteoarthritis. *Arthritis Care & Research*, 65(12), 2051-2055.
doi:10.1002/acr.22073
- Toscos, T., Daley, C., Heral, L., Doshi, R., Chen, Y., Eckert, G., ... Mirro, M. (2016). Impact of electronic personal health record use on engagement and intermediate health outcomes among cardiac patients: A quasi-experimental study. *Journal of American Informatics Association*, 23, 119-128. doi:10.1093/jamia/ocv164

- Tse, M., Wan, V., & Wong, A. (2013). Pain and pain-related situations surrounding community-dwelling older persons. *Journal of Clinical Nursing*, 22, 1870-1879.
doi:10.1111/jocn.12238
- van Kleef, E., van Trijp, H., & Luning, P. (2005). Consumer research in the early stages of new product development: A critical review of methods and techniques. *Journal of Food Quality and Preference*, 16, 181-201. doi:10.1016/j.foodqual.2004.05.012
- Vedel, I., Akhlaghpour, S., Vaghefi, I., Bergman, H., & Lapointe, L. (2013). Health information technologies in geriatrics and gerontology: A mixed systematic review. *Journal of the American Medical Informatics Association*, 20, 1109-1119.
doi:10.1136/amiajnl-2013-001705
- Wald, J., Businger, A., Gandhi, T., Grant, R., Poon, E., Schnipper, J., ... Middleton, B. (2010). Implementing practice-linked pre-visit electronic journals in primary care: Patient and physician use and satisfaction. *Journal of the American Informatics Association*, 17, 502-506. doi:10.1136/jamia.2009.001362
- Weiss, B., Mays, M., Martz, W., Castro, K., DeWalt, D., Pignone, M., ... Hale, F. (2005). Quick assessment of literacy in primary care: The newest vital sign. *Annals of Family Medicine*, 3(6), 514-522. doi:10.1370/afm.405
- Whyte, W. H. (1952). *Is anybody listening*. New York, NY: Simon and Schuster.
- Williams, C., Templin, T., & Mosley-Williams, A. (2004). Usability of a computer-assisted interview system for the unaided self-entry of patient data in an urban rheumatology clinic. *Journal of the American Medical Informatics Association*, 11(4), 249-259.
doi:10.1197/jamia.M1527

- Wilkie, D., Judge, K., Berry, D., Dell, J., Zong, S., & Gillespie, R. (2003). Usability of a computerized PAINReportIt in the general public with pain and people with cancer pain. *Journal of Pain and Symptom Management*, 25(3), 213-224.
doi:10.1016/S0885-3924(02)00638-3
- Youngblut, J., & Brooten, D. (1999). Alternate child care, history of hospitalization, and preschool child behavior. *Nursing Research*, 48(1), 29-34. Retrieved from <https://journals.lww.com/nursingresearchonline/pages/default.aspx>
- Youngblut, J., Brooten, D., Singer, L., Standing, T., Lee, H., & Rodgers, W. (2001). Effects of maternal employment and prematurity on child outcomes in single parent families. *Nursing Research*, 50(6), 346-355. Retrieved from <https://journals.lww.com/nursingresearchonline/pages/default.aspx>
- Younger, J., McCue, R., & Mackey, S. (2009). Pain outcomes: A brief review of instruments and techniques. *Current Pain and Headache Reports*, 13(1), 39-43.
doi:10.1007/s11916-009-0009-x
- Zalon, M. (2006). Using and understanding factor analysis: the brief pain inventory. *Nurse Researcher*, 14(1), 71-84. Retrieved from <https://rcni.com/nurse-researcher>
- Zhang, W., Nuki, G., Moskowitz, R., Abramson, S., Altman, R., ... Kwoh, H. (2010). OARSI recommendations for the management of hip and knee osteoarthritis Part III: Changes in evidence following systematic cumulative update of research published through January 2009. *Osteoarthritis and Cartilage*, 18, 476-499. doi:10.1016/j.joca.2010.01.013

Table 1

Phase 1 Coded Data for Positive Features

Version	Examples of Positive Features Comments
<i>The following comments were about an imagined future version of the computerized PMLHC:</i>	<p>I think...for a patient being able to update what's changed is helpful.</p> <p>But this idea of a launch to (software) pain history I think is great and very useful.... holistic.</p> <p>What's nice is the reaching out to the patient to give us a history.</p> <p>Get it imbedded into a medical record like EPIC it will be a big deal.</p>
<i>The remaining comments were about the working model of the computerized PMLHC output:</i>	<p>It reinforces what we recommend.</p> <p>It doesn't look like it's too complicated or complex. p10 [provider looking at printout for their own use]</p> <p>If I didn't have that I wouldn't be assessing their pain very well. I get it. more focused. I like the idea.</p> <p>It helps them be mindful. Like, a patient should be more mindful of things, too like putting them in the process.</p> <p>Certainly, as a visual that could be helpful. (Referring to red, green, and black data entries)</p> <p>I think if we can supply this is how we are we are getting at their sense of pain (use of PMLHC) it can only help the rapport.</p> <p>It's certainly a good start, I think it's more than we have in one place coherently...have had access to...</p> <p>It would be really hard to get to without this kind of detailed, very organized history, and I'm liking it more as we go.</p> <p>It also fosters partnering with us that they have to give us some information and we can't just extract it all the time.</p>

Table 2

Phase 1 Coded Data for Support of Feasibility

Version	Examples of Support of Feasibility
<i>The following comments were about an imagined future version of the computerized PMLHC:</i>	<p>They can do this kind of stuff from their phone I-pad, from any interface.</p> <p>It would definitely be helpful to have this before. I wouldn't be able to give this to the patient while I'm seeing them... So when they're done filling something out like this do they get to see it in its whole before they come in to the office with us?... I think it's a good idea because then they know where we're coming from.</p> <p>But we could easily incorporate it into the work flow that anybody with chronic pain whether or not they are on opiates needs a follow up within x amount of time and that this is part of the process.</p> <p>They could do it from their own tablet. [Or]..you could have locked down tablets where people could run over and enter that stuff for people that don't have tablets or portable devices...I think it could be helpful if it punches all of this out and you could get right to the discussion.</p>
<i>The following comments were about the working model of the computerized PMLHC output:</i>	<p>The idea is you're really setting up the provider for success during that visit.</p> <p>This is something the patient did fill before the visit, the question should be why they've stopped using NSAID. Putting their pain history in one place is critically important. I can't imagine that that would exist already.</p> <p>If the point of this tool is to determine whether treatment needs to be updated or not I think it's still very useful.</p> <p>Time is the issue if I don't have to fill this out and the patient's definitely gonna get it done and presented to me in a way that doesn't slow me down, then I'm probably all for it.</p> <p>I think this will be useful.</p>

Table 3

Phase 1 PMLHC Affirmations Cluster

Subcategory	Examples of Provider Comments
Potential advantages of a computerized PMLHC	<p>Get it imbedded into a medical record like EPIC it will be a big deal.</p> <p>I think...for a patient being able to update what's changed is helpful.</p> <p>But this idea of a launch to (software) pain history I think is great and very useful.... holistic.</p> <p>It reinforces what we recommend.</p>
Improved communication to support collaborative provider-patient relationships	<p>I think having it in front of us, we could sort of target questions.</p> <p>It helps them be mindful. Like, a patient should be more mindful of things, too like putting them in the process.</p> <p>I think if we can supply this is how we are we are getting at their sense of pain (<i>use of PMLHC</i>) it can only help the rapport.</p> <p>It also fosters partnering with us that they have to give us some information and we can't just extract it all the time.</p> <p>I think it can help with our relationship with the patient that we are interested in this information over time and it's not just about how are you feeling today.</p>

Table 4

Phase 1 Areas of Concern Cluster

Subcategory	Examples of Provider Comments
Dislike of concept and output format	<p>This is overwhelming. This actually overwhelms me a little bit.</p> <p>I can't think of anything about this that I like and is going to help me. I mean, there is too much data as it is already on every single patient. The last thing that you need is 100 different things that they tried that may have helped them in 2008...I don't know...that doesn't work for me...this form.</p> <p>Needing to know a little bit more about what this data really means.</p>
Patient challenges	<p>Maybe "functioning" may throw people but it is simple we can't assume.</p> <p>The tech ability of some people is maybe going to be an eliminating factor. I have some older people who are pretty active on the computer, but I think as a general rule...</p> <p>I see the date or this being maybe a problem...people might have trouble working through...</p> <p>We tend to have a vulnerable, medically illiterate, more transient population.</p>
Workflow challenges	<p>Probably would need to be like a few minutes so it doesn't slow the rooming process, the work flow.</p> <p>I'm thinking it has to be simple... that you can process it in less than a minute...because if it's going to take more than five minutes to read it and I only have 15 minutes with the patient, that's not going to work.</p> <p><i>Having patient explain their answers ...and again that would take an hour at least.</i></p>

Table 5

Phase 1 Missing Features and Ideas for PMLHC Development

Subcategory	Examples of Provider Comments
Need for assessment of patient perceptions and goals	<p>You could have that goal question just be at that present visit.</p> <p>You could give a very simple drop down; to be pain free; to live better with my pain; to function better.</p> <p>What are your goals with your pain? In addition in this past history, in your mind, what has been a barrier to achieving those goals?... I wonder if with each recollection barrier to improvement at that point in time is another category... barriers kind of forces them to see what other things may have been going on.</p> <p>The patient's perception of each of these things... The patient's perception on how well their pain was addressed... So could there be a third category?</p>
PMLHC output	<p>Did you guys play around with a grid?...with pluses or minuses or something...I could hone in right, you know, on what I need to hone in on.</p> <p>Maybe you could have two dates... start and stop, or something. You could even have two pluses or a degree of improvement instead of just plus or minus. "Oh, that really helped a lot." You could have three pluses, as opposed to the typical scale.</p>
Optimizing electronic health record capabilities	<p>You'd have to send an assignment to the patient prior to the visit if you wanted them to fill it out electronically before that visit.</p> <p>Should they have to update their own personal history? ...</p> <p>Should the patient have the ability to update their history?</p> <p>Anything that's new would have to be a different color so it will prompt us to see what's new like in maybe blue or purple, or highlighted...since the last time they saw us. something visually...like a star or checkmark since last visit.</p> <p>Any time there is a change in the symptoms and the function, we would like to know from the patient, updating sounds like a good option...if we got notification in our box saying Mary Smith has edited her pain survey or something which might be potentially helpful.</p>

Table 6

Phase 2 Older Adults' PMLHC Affirmations Cluster

Subcategory	Number of comments	Exemplar comments
General Positive Comments	24 (from 16 participants)	I thought it was excellent. Well planned, easy to follow. (Participant 25a)
Liked Electronic Health Records	3 (from 3 participants)	The questions were very simple and direct to people with arthritis. (Participant 27a) [Electronic health records are] very good...and you can pop the stuff like you can refer right back to the last time you had a tooth pulled or something. (Participant 5a) I do feel [an electronic health record] is safe, yeah. (Participant 21a)
PMLHC was Thorough	6 (from 6 participants)	No, I don't have any suggestions, because it covers everything, how I function and the pain I endure. (Participant 15a) I think it was very thorough with the questions. (Participant 19a)
Believed the PMLHC to be Helpful	4 (from 4 participants)	...You're getting the information that's going to probably try to help us or help somebody else, too. (Participant 5a) I thought it was good that you were able to segregate the different treatments that you had, and to be able to document, and have somebody listen, and tell you it's not in your head. (Participant 25a)
Increased Older Adults' Self-Awareness of Pain Management	8 (from 8 participants)	One thing it certainly has made me think a lot about what I'm doing, what I have done, what I might do differently, to make life better. (Participant 15a) Made me think of back when it all started... (Participant 19a)

Table 7

Phase 2 Older Adults' Areas of Concern Cluster

Subcategory	Number of comments	Exemplar comments
General Negative Comments	8 (from 7 participants)	I wish that it was different, because it kind of boxed you in. You have to use what's said there rather than saying it your own words. (Participant 18a) I think a lot of it was repetitive. (Participant 26a) I have a tendency to find the doctors kind of very resistant to take something new that they don't recommend. (Participant 11a)
Dislike for Computers	7 (from 6 participants)	I'm not that much of a fan of computers, doing stuff on it. I'm still paper and pencil. I think it's more private. (Participant 4a) I don't like a computer to that extent where I want to reveal all my information. (Participant 6a)
Difficulty Filling Out the PMLHC	5 (from 5 participants)	No, I didn't read on. It was my fault. (Participant 12a) I wasn't sure what parts were which parts. Did it go every 5 years, or did it go every 10 years? Or something like that? (Participant 5a)
Doesn't Tell the Whole Story	4 (from 3 participants)	About the program, is it didn't tell the whole story...because, initially, with PT the pain increased, the mobility decreased. But, long term, both the pain... well the pain decreased, and the mobility increased. (Participant 23a)
Difficulty Remembering Details	8 (from 7 participants)	It's hard to put on the computer what really happened. (Participant 8a) It's very difficult to go back and know exactly what month you went on and so forth. (Participant 5a) I don't dwell on the past so if you say, "When did you have this operation?" I don't know, somewhere around 10 years ago. I just don't focus on the past. (Participant 9a)

Table 8

Phase 2 Older Adults' Missing Features and Ideas for PMLHC Development

Topic	Number of comments	Exemplar comments
Suggestions used to edit versions of PMLHC		
Ability to specify body part	2 (from 2 participants)	Arthritis is in a lot of different places, right?...I didn't explain different parts of my body.
Ability to skip to the end of instrument	1 (from 1 participant)	Needing a way to skip to the end because we didn't need that many rounds of questions.
Needed a back button	2 (from 2 participants)	Is there a way of going back on these so I can correct something?
Preface introduction to explain rounds of treatments	1 (from 1 participant)	You may want to preface it too, that there'll be multiple rounds, so that when you start off, you start with that in mind.
Ability to fill in details for "other" treatments	4 (from 4 participants)	Well you know, you look at the thing and it gives you a question and you try to answer it. Then you say you can't do it... (<i>wanted to write in chiropractor</i>)
Needed to correct available date ranges	4 (from 4 participants)	If you could put in when I said it started 'cause that's as far as you went back, but maybe if you went 10 years later? The one problem where it didn't have up to the current date.
Additional suggestions not used to edit PMLHC		
Add a place to describe adverse reactions	1 (from 1 participant)	I do have a suggestion that you add, for pain management, if you have a reaction to any of the medications...
Add journal style entries	1 (from 1 participant)	I would like to know too, with arthritis is there any particular time of year that it's more painful, or more reactive. Does the weather have an influence?
Clarify treatment outcomes	1 (from 1 participant)	Well, just the clarity of the questions, ... It didn't say long term.
Ask if symptoms were sudden or gradual onset	1 (from 1 participant)	Well, it doesn't ask if this was a sudden onset when the problem started.
Find ways to allow more detailed answers	1 (from 1 participant)	Also, sometimes the PT is very strenuous...sometimes it works, sometimes it doesn't, and you can't in general give an indication.
Ability to specify preventative treatments	1 (from 1 participant)	Int: <i>if it had a question asking you how you use this brace?</i> Part: I suppose that's what it is, helps with the pain...prevent the pain.
Record date in ranges instead of specific years	1 (from 1 participant)	It pinned me down to a date. It really pinned me down to one date where it was really a period of time more, rather than one date of me doing...

Table 9

Phase 2 Participants Cross Referenced to PMLHC Versions and Edits

Participants	PMLHC Version	Edits from previous version
1, 2, 3 (Focus group)	1	(Not applicable)
4a, 5a, 6a	2	Edited instructions to add clarity about rounds of treatments
7a	3	<p>Changed outcomes questions to table format with all 5 choices in one table (pain increase/decrease; function increase/decrease; or symptoms did not change)</p> <p>Corrected date range to include current year</p> <p>Added back buttons to allow editing of responses</p>
8a, 9a, 10a, 11a	4	<p>Back/next buttons changed to include words (back/next as well as directional arrows)</p> <p>BPI SF added (trial of computer version for testing)</p> <p>Added ability to skip to end</p> <p>Split outcomes to 2 tables – pain and function (decluttered and forced choices for both outcomes)</p>
12a	5	Minor wording changes only to aid navigating sections
13a, 14a, 15a	6	<p>Added IRB invitation screen with seal</p> <p>Computer adaptation of BPI SF in final accepted format</p> <p>Added demographics and computer use questions</p> <p>Increased to 10 rounds of possible treatment regimes</p> <p>Added fill in space for “other” treatment choice</p> <p>Added body part question for each round to identify which part treatment round refers to</p>
18a, 19a, 20a, 21a, 23a, 25a, 26a, 27a, 28a	7	Enhanced instructions about exercise as a treatment option

Table 10

Phase 2 Participants' PMLHC's Rounds of Treatments and Outcomes

Participant	Number of Rounds Recorded	Earliest year recorded	Number of treatments (N = 123)	Positive outcomes (N = 194)	Negative outcomes (N = 10)	No Change Outcomes (N = 41)
13a	2	1992	6	12	0	0
14a	1	2016	1	2	0	0
15a	3	2006	8	13	0	3 (2 pain, 1 function) *
18a	4	1999	33	53**	2 (function)	8 (4 pain, 4 function)
19a	5	1977	20	37	1 (pain)	2 (1 pain, 1 function)
20a	2	2000	2	2	0	2 (1 pain, 1 function)
21a	5	2010	11	14	2 (1 pain, 1 function)	6 (2 pain, 4 function)
23a	2	2003	7	8	2 (function)	4 (2pain, 2 function)
25a	3	2012	12	21**	3 (1 pain, 2 function)	1 (pain)
26a	5	2010	11	20	0	1 (function)
27a	1	No date	4	4	0	4 (2 pain, 2 function)
28a	6	1993	8	8	0	8 (4 pain, 4 function)

*Note: pain refers to pain intensity outcome, function refers to pain interference with function outcome. ** Two participants recorded multiple outcome choices for some treatments.

Table 11

Phase 2 Participants Arthritis Sites and Treatments

Participant	Arthritis Site(s)	Total Joint Replacement?	Use Exercise?	Acetaminophen or NSAIDs?
13a	Neck, Back, Elbow, Wrist, Hands, Shoulder, Ankles	No	Yes	NSAIDs
14a	Hands	No	Yes	n/a
15a	Legs, Knee, Neck, Back	Total Knee	Yes	NSAIDs
18a	Knee, Shoulder, Neck, Back, Hands	No	Yes	Acetaminophen
19a	Hip, Back, Shoulder, Wrist, Hands	No	Yes	Acetaminophen
20a	Hip, Knees	Bilateral Total Hips and Knees	No	Acetaminophen
21a	Back, Knee	No	No	NSAIDs
23a	Back	No	Yes	Acetaminophen
25a	Knee, Neck, Back	No	Yes	NSAIDs
26a	Knee	No	Yes	Acetaminophen
27a	Knee, Neck, Back	Bilateral Total Knees	Yes	Acetaminophen
28a	Knees, Shoulder, Neck, Hands, Hip	Total Knee	No	NSAIDs

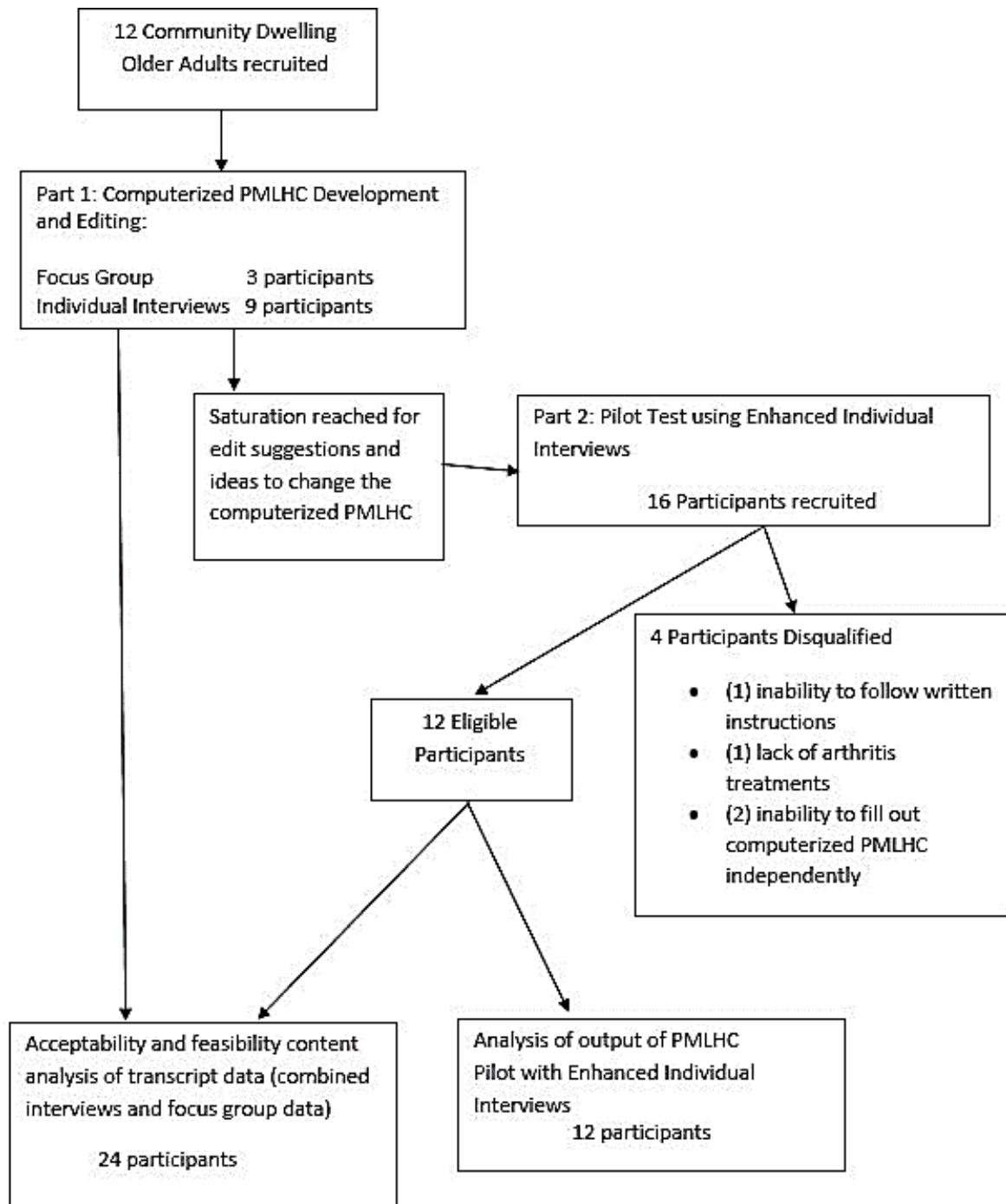


Figure 1. Phase 2 participant inclusion.

Appendix A: Theory of Trialing to Pain Control

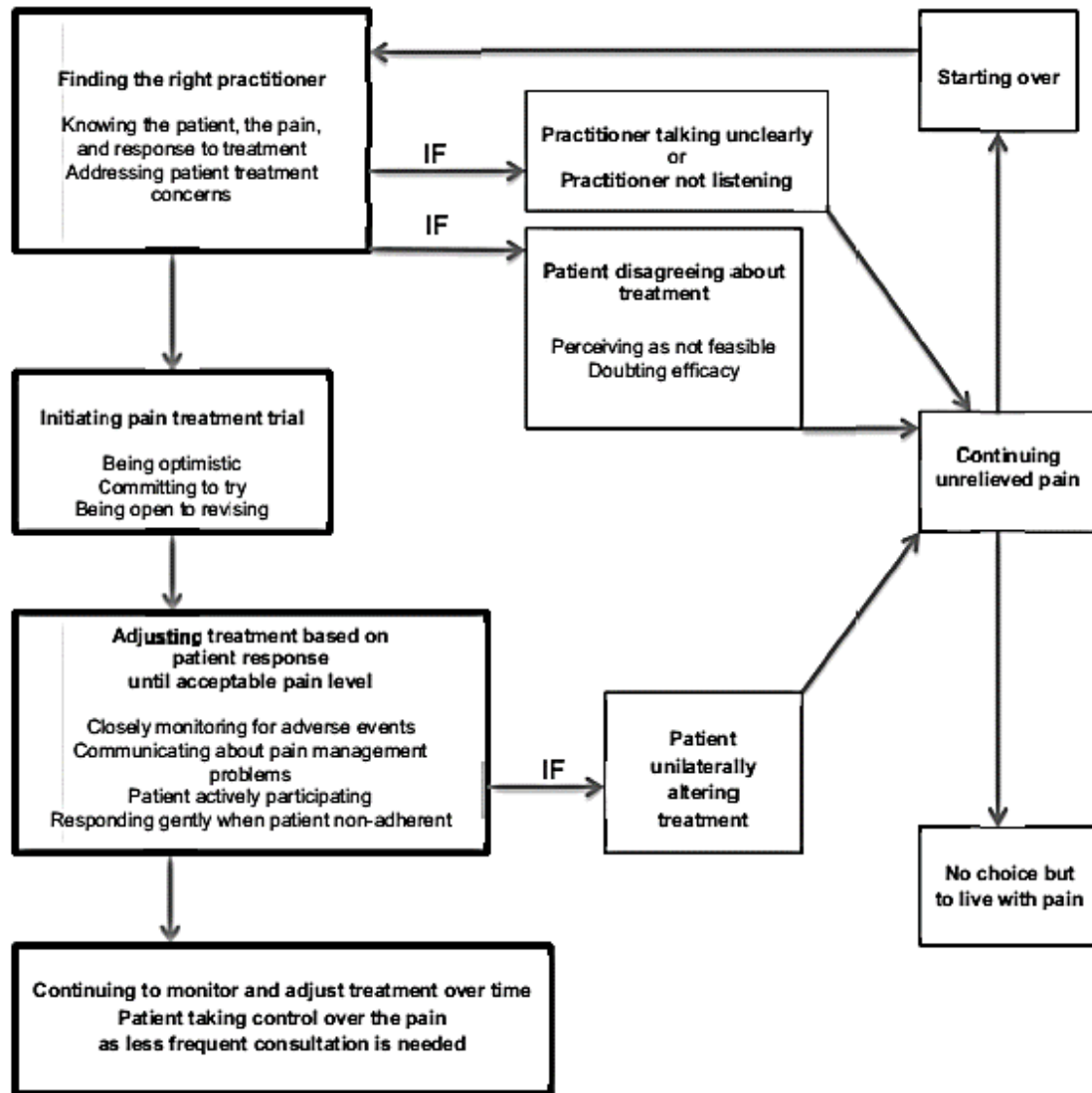


Figure A1. Theory of trialing to pain control. Adapted from “trialing to pain control: A Grounded Theory,” by D. D. McDonald, 2014, *Research in Nursing & Health*, 37, p. 110. Copyright [2014] by Wiley Periodicals, Inc. Reprinted with permission.

Appendix B: Provider Participant Demographic Form

Participant Name _____

Age _____

I identify my gender as:

- ☐ Female
- ☐ Male
- ☐ Trans*
- ☐ I prefer not to say

Ethnicity:

- ☐ White, non-Hispanic
- ☐ White, Hispanic
- ☐ African American

Professional role _____ (MD, APRN, NP, PA, other)

Years in Primary Care Practice _____

Previous Clinical experience (if applicable)

Educational Background _____

Computer Experience:

Do you use an electronic medical record as the primary record keeping in your practice?
Yes / No

(If Yes, how long have you been using an electronic medical record? _____ years)

Do you use email to communicate directly with any of your patients? Yes / No

Do you use any other forms of electronic communication directly with any of your patients?
(text, social media, instant messaging...) Yes / No

Appendix C: Phase 1 Fictitious Patient PMLHC Printout

Patient ID: Mary Smith

Green	Positive response	<ul style="list-style-type: none"> • Decrease pain • Increase function
Red	Negative response	<ul style="list-style-type: none"> • Increase pain • Decrease function
Black	Neutral	Either did not change outcomes, or was not reported with an outcome.

June, 2005

Pain: Acetaminophen & Exercise

Functioning: Acetaminophen & Exercise

September, 2008

Pain: Acetaminophen & Glucosamine & Exercise & Applying Heat or Cold & Chondroitin

Functioning: Acetaminophen & Glucosamine & Exercise & Applying Heat or Cold & Chondroitin

January, 2010

Pain: Acetaminophen & Glucosamine & Exercise & Prescribed Physical Therapy & Rest & Chondroitin

Functioning: Acetaminophen & Glucosamine & Exercise & Prescribed Physical Therapy & Rest & Chondroitin

May, 2013

Pain: NSAIDS & Glucosamine & Exercise & Assistive Devices & Chondroitin

Functioning: NSAIDS & Glucosamine & Exercise & Assistive Devices & Chondroitin

February, 2014

Pain: Glucosamine & Prescribed Opioids & Exercise & Prescribed Physical Therapy & Massage
& Chondroitin

Functioning: Glucosamine & Prescribed Opioids & Exercise & Prescribed Physical Therapy &
Massage & Chondroitin

Pain= pain intensity

Functioning = Pain interfering with functioning

Appendix D: Provider Focus Group Discussion Guide

Introduction:

- Thank participants for their time and make introductions as appropriate
- Offer to discuss informed consent or answer any additional questions that anyone has regarding the study
- Housekeeping issues: where are bathrooms, refreshments (if any), when compensation will be paid (if there is any), how long the session is expected to take (60-90 minutes)
- Distribute demographic forms, allow time to fill them in, and then collect them (finish this item before discussion begins to keep people focused on the speakers and topic).
- Review the purpose of the group (to elicit opinions and ideas regarding a proposed computerized pain management life history calendar (ePMLHC) that patients would work on prior to office visits).

Group ground rules (will be posted on the wall)

- One speaker at a time.
- Please allow that there may be differences of opinion and be respectful of each other.
- You are encouraged to converse with and respond directly to each other
- All ideas are welcome (and encouraged).
- We are recording the session, but all names will be excluded from all reports so your comments are anonymous.
- Please put cell phones in quiet mode.

Topics of conversation

- As the PMLHC printout is distributed to participants they will be asked to consider the following patient scenario:
 - Mary, a 68-year-old retired school teacher is in today because her knees have become increasingly more painful. She has a history of osteoarthritis in both knees diagnosed 4 years ago. She hands you the printout of the PMLHC and asks if she can discuss her knee arthritis pain with you.
- What are your feelings about a patient filling out an assessment form like this one ahead of time?
- What are your general impressions of the printout of the PMLHC?
 - How long or short should the printout be to be most helpful?
 - What additional information (if any) do you think is missing from the printout?
 - What additional suggestions would you like to make?
- What additional questions would you like to ask the patient as a result of reading the printout?
- Please reflect on your own practice as you review the PMLHC and discuss how you could incorporate a review of this printout as part of a normal office visit?
- What are the barriers, if any, in your practice to using the PMLHC? (Either your own or the facility?)

Follow up questions (to clarify discussion points and elicit more opinions from other members of the group as the discussion progresses).

- Summarize what has been said and ask if the group agrees

- Ask if there are others that want to comment on something just said (make brief eye contact with all members – especially if there are members who have not yet spoken)
- Ask follow up questions

** Neutral Probes:

- Can you give me more details on what you just shared?
- Can you elaborate on your thoughts a little more?
- Anything else?
- Why do you feel this way?

Conclusion

I would like to thank everyone for their participation today!

Appendix E: Patient Participant Demographic Form

Demographics:

Participant Name _____

Age _____

I identify my gender as:

- ☐ Female
- ☐ Male
- ☐ Trans*
- ☐ I prefer not to say

Ethnicity:

- ☐ White, non-Hispanic
- ☐ White, Hispanic
- ☐ African American
- ☐ Native American
- ☐ Other _____

Marital status:

- ___ Married
- ___ Divorced
- ___ Widowed
- ___ Domestic Partnership
- ___ Never Married

Retired? **Yes / No** ... If no...Type of employment? _____

Have you had any total joint replacements? **Yes / No** If yes what joint(s)? _____

How often do you typically talk to your provider about your arthritis pain? _____

Do you regularly use a computer, smartphone, or tablet? **Yes / No**

Do you own your own computer, smartphone, or tablet? **Yes / No**

If yes, what kind of device(s) do you own? _____

What do you typically use your computer or device for? _____

Do you use email to communicate directly with any of your health care providers? **Yes / No**

Do you use any other forms of electronic communication directly with any of your health care providers? (text, social media?, instant messaging...) **Yes / No**

(If yes, what kind? _____)

Appendix F: Screen Shots of Final Version of Computerized PMLHC

The screenshot displays a web browser window with the URL https://uconn.co1.qualtrics.com/jfe/form/SV_4U9OqFugOQm8HX. The page features a dark blue header with the UCONN logo. The main content area is white and contains the following text:

Research study seeks participants 65 and older:

You are invited to participate in a research study that is being conducted by Jennifer Hehl, a nurse doctoral student in the School of Nursing at UConn. The research study is about developing and testing a computerized Pain Management Life History Calendar to be used by patients with osteoarthritis pain. A computerized Pain Management Life History Calendar may help patients describe and discuss all of the treatments they have used over time for their osteoarthritis pain and the effect of each treatment on their pain. The purpose of this research study is to help improve pain management discussions between providers and patients.

If you participate, in this study, you will be asked to fill out a one-time computer assessment form. The time to fill out the assessment is expected to take approximately 10-15 minutes of your time. You will not be asked to provide your name or contact information and you will not be contacted after filling out the assessment form for any further information.

If you are:

- 65 years of age or older
- Have osteoarthritis pain
- And you would like to ask for more information about the study, please call or email the student researcher:

Jennifer Hehl, RN
University of Connecticut, Storrs Campus
School of Nursing, Graduate Program
jshanaman@gmail.com
cell number: 860-985-5852

If you would like to participate in the study, please click Next below.

Below the text, there is a small UCONN IRB logo and a "Show all" button. The browser's address bar and taskbar are visible at the bottom of the screenshot.

Who wears the pa...pdf

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UConn

Please read the following information describing your participation in a research study and if you are comfortable participating, at the end, please choose "Next" and you will be directed to the beginning of the study.

At any time, you may stop participating and exit the study. Thank you for your interest in this study!

University of Connecticut
Principal Investigator: Deborah Dillon McDonald
Student Researcher: Jennifer M. Hehl
Study Title: Development of a Computerized Pain Management Life History Calendar

Introduction

You are invited to participate in a research study to fill out a computer assessment describing your history of osteoarthritis pain and the different treatments that you have tried over time. You are being asked to participate because you are an adult over the age of 65 who has osteoarthritis pain.

Why is this study being done?

This research study is about developing and testing a computerized Pain Management Life History Calendar to be used by patients with osteoarthritis pain. A computerized Pain Management Life History Calendar will be able to help patients describe and discuss all of the treatments they have used over time for their osteoarthritis pain and the effect of each treatment on their pain. The purpose of this research study is to see if patients can successfully fill out this form on their own. Having these histories of how people have treated their osteoarthritis pain over the years will allow researchers to look at trends over time.

What are the study procedures? What will I be asked to do?

If you agree to take part in this study, you will be asked to take a one time computer assessment describing your past and present osteoarthritis treatments and the results you had from them. The study is expected to take approximately 10 – 20 minutes of your time and you will not be contacted after you have finished the online questionnaire.

- **Demographics:** You will be asked to fill out a demographic form that asks for basic information about your physical symptoms from your osteoarthritis and some background information about your gender, marital status, and your use of computers.
- **Filling out a computerized Pain Management Life History Calendar:** If you choose to participate you will next be directed to the start of your Pain Management Life History Calendar. The Pain Management Life History Calendar is a series of questions designed to help you record all of the treatments and their outcomes that you have tried since first beginning to treat the pain from your osteoarthritis. It is possible that you may feel uncomfortable answering some of the questions. There are no physical risks associated with the form and you may always choose not to answer a question that makes you feel uncomfortable.

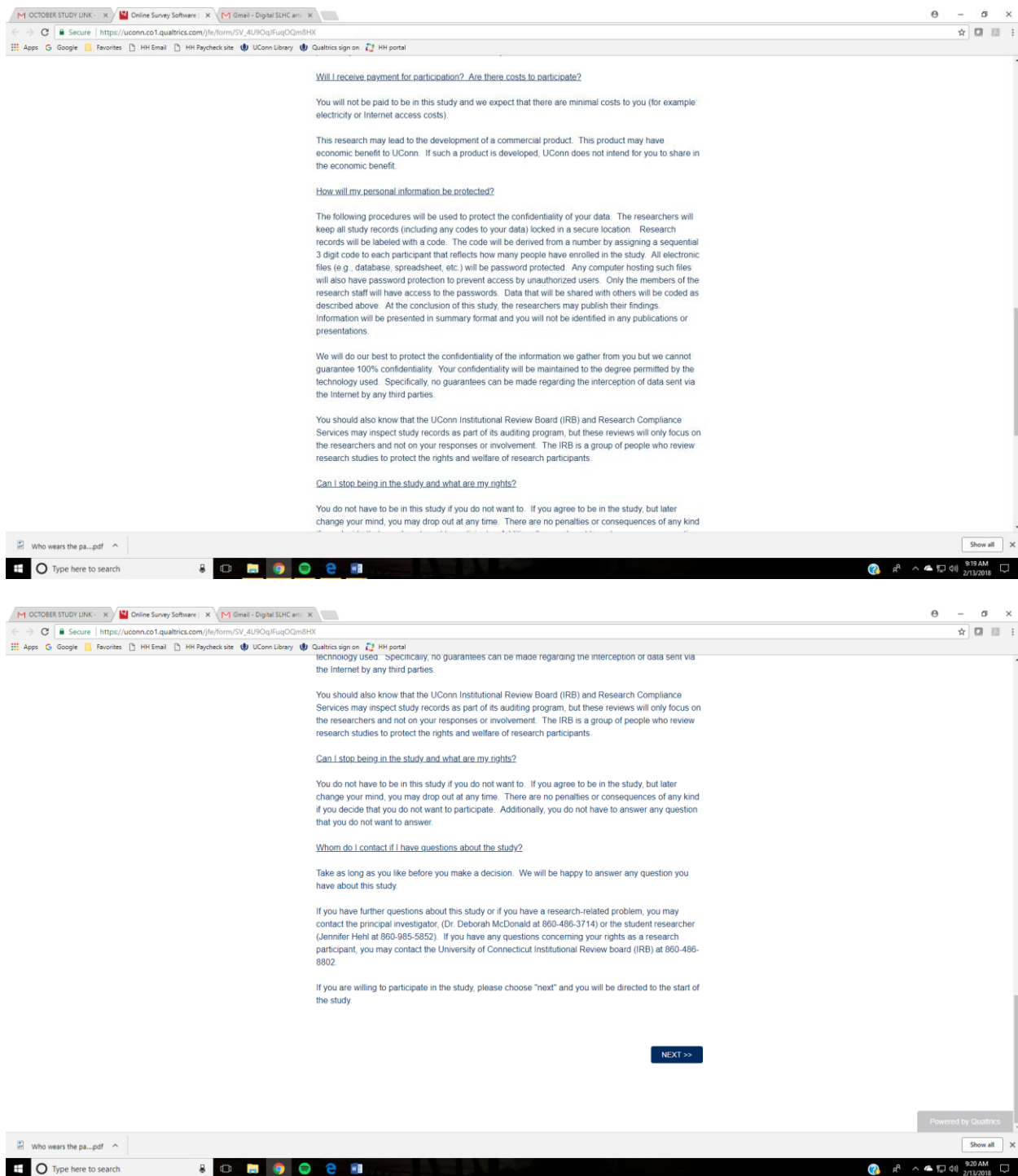
What are the risks or inconveniences of the study?

We believe there are no known risks associated with this research study, however, a possible inconvenience may be the time it takes to complete the study. It is also possible that you may feel uncomfortable answering some of the questions. There are no physical risks associated with the forms and you may always choose not to answer a question that makes you feel uncomfortable.

What are the benefits of the study?

You may not benefit directly from the information we gather in this study however, your participation in the study may allow you to use the information from your computerized Pain Management Life History Calendar to start a discussion with your provider about your osteoarthritis pain management. Additionally, people who have the same condition may benefit in the future. There is also the possibility that no benefit will come from this study.

Will I receive payment for participation? Are there costs to participate?



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Thank you for taking the time to fill out a Pain Management Life History Calendar!
This section will ask some basic information about you...

What is your age?

I identify my gender as:

☐ Female
☐ Male
☐ Trans*
☐ I prefer not to say

I identify myself as:

☐ White, non-Hispanic
☐ White, Hispanic
☐ African American
☐ Native American
☐ Asian
☐ Other

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Marital Status:

☐ Married
☐ Divorced
☐ Widowed
☐ Domestic Partnership
☐ Never married

Retired?

☐ Yes
☐ No, if no... what type of employment?

Have you had any Total or Partial Joint Replacements?

☐ Yes, if yes, what joints?
☐ No

How often do you typically talk to your provider about arthritis pain?

Do you regularly use a computer, smart-phone or tablet?

☐ Yes
☐ No

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☐ Yes
☐ No

Do you own your own computer, smart-phone or tablet?

☐ Yes (if yes, what kind of device(s) do you own?)
☐ No

What do you typically use your computer or device for?

Do you use email to communicate directly with any of your health care providers?

☐ Yes
☐ No

Do you use any other forms of electronic communication directly with any of your health care providers? (texts, social media, instant messaging, etc...)

☐ Yes (if yes, what kind?)
☐ No

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The next series of questions* will ask you about your current experience with pain.

(*These questions have been adapted from the Brief Pain Inventory (Short Form)
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Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

☐ Yes

☐ No

<< BACK

>> NEXT

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Please describe the area(s) of your body where you feel pain.

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Restart Survey

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Please rate your pain by marking the box beside the number that best describes your pain at its WORST in the last 24 hours.

No Pain

Pain as Bad as You Can Imagine

0

1

2

3

4

5

6

7

8

9

10

Please rate your pain by marking the box beside the number that best describes your pain at its LEAST in the last 24 hours.

No Pain

Pain as Bad as You Can Imagine

0

1

2

3

4

5

6

7

8

9

10

Please rate your pain by marking the box beside the number that best describes your

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Close Preview

Restart Survey

Place Bookmark

Please rate your pain by marking the box beside the number that best describes your pain on the AVERAGE.

No Pain

Pain as Bad as You Can Imagine

0

1

2

3

4

5

6

7

8

9

10

Please rate your pain by marking the box beside the number that tells how much pain you have RIGHT NOW.

No Pain

Pain as Bad as You Can Imagine

0

1

2

3

4

5

6

7

8

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>> NEXT

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In the last 24 hours, how much relief have pain treatments or medications provided? Please mark the box below the percentage that most shows how much RELIEF you have received.

No Relief - 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	Complete Relief - 100%
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

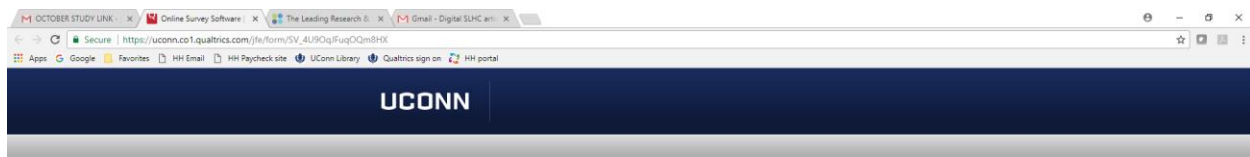
Mark the box beside the number that describes how, during the past 24 hours, pain has interfered with your:

	Does Not Interfere 0	1	2	3	4	5	6	7	8	9	Completely Interferes 10
General Activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Mark the box beside the number that describes how, during the past 24 hours, pain has interfered with your:

	Does Not Interfere 0	1	2	3	4	5	6	7	8	9	Completely Interferes 10
General Activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking Ability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Normal Work (includes both work outside the home and housework)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relations with other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enjoyment of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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[This next section will be the content of the Pain Management Life History Calendar.](#)

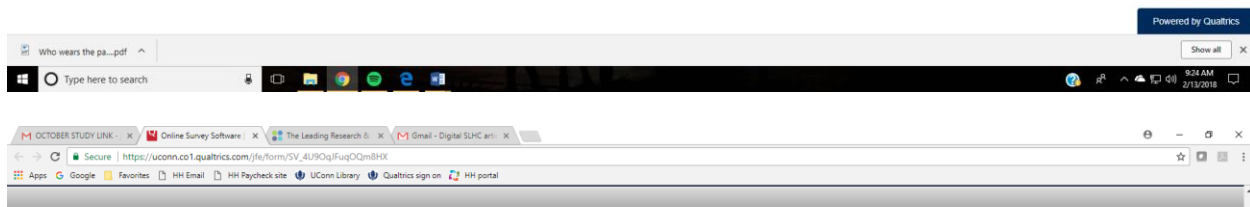
For the following questions you will be asked to think about each time you changed your treatments and or medications for your arthritis. It may be helpful to think about times in your life when pain or discomfort from your arthritis interfered with your actions or plans as a way to remember when you tried certain treatment options or when you changed treatment plans.

After you describe each round of treatments and medications, you will be asked to think about when you changed your pain management plan (change in medications or change in therapies) and then you will describe that new treatment plan.

You may use as many or as few rounds of treatment plans as you think you need to describe your history of arthritis treatments. The last round will be to describe your current arthritis treatments and medications.

<< BACK

NEXT >>



To begin, please think about when you first experienced pain from your arthritis. As close as you can remember please tell us the year (and month) you can remember the pain starting. It might help to remember other events in your life that were happening at the same time that your arthritis pain first needed treatment.
(Choose the year and month from the following drop down menus)

Year
Month

If you have arthritis in more than one body part, what part(s) of your body was this round of treatments for?

- ☐ Knee
- ☐ Hip
- ☐ Shoulder
- ☐ Neck
- ☐ Back
- ☐ Elbow
- ☐ Wrist
- ☐ Hands
- ☐ Ankles
- ☐ Feet
- ☐ Other

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As you think about the treatments you have used to help treat your arthritis, please remember that physical activity is considered a treatment, too!

Which treatment option(s) did you try **first** to decrease your pain?
(Choose only the ones that you tried as your **first set** of treatments.)

- ☒ Exercise (biking, walking, swimming, or other)
- ☐ Acetaminophen (Tylenol)
- ☒ NSAIDS: Ibuprofen - (Motrin, Advil), Naproxen - (Aleve), Aspirin - (Excedrin, Bufferin, Bayer)...
- ☐ Topical agents (Mineral Ice, Icy Hot, Capzasin, Aspercreme, Bengay, ...)
- ☐ Prescribed Opioids (oxycodone, hydrocodone, Codeine, Tramadol...)
- ☒ Glucosamine
- ☒ Chondroitin
- ☐ Cortisone injection
- ☐ Prescribed Physical Therapy
- ☒ Applying Heat or Cold
- ☐ Massage
- ☐ Assistive Devices (cane, shoe lift, brace...)
- ☐ Positioning
- ☐ Rest
- ☐ Joint Replacement Surgery (Total Hip, Total Knee, Birmingham Hip Resurfacing, Total Shoulder, Patella-Femoral Joint Arthroplasty, ...)
- ☐ Other treatment not listed here
- ☐ No Treatment

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- ☒ Exercise (biking, walking, swimming, or other)
- ☐ Acetaminophen (Tylenol)
- ☒ NSAIDS: Ibuprofen - (Motrin, Advil), Naproxen - (Aleve), Aspirin - (Excedrin, Bufferin, Bayer)...
- ☐ Topical agents (Mineral Ice, Icy Hot, Capzasin, Aspercreme, Bengay, ...)
- ☐ Prescribed Opioids (oxycodone, hydrocodone, Codeine, Tramadol...)
- ☒ Glucosamine
- ☒ Chondroitin
- ☐ Cortisone injection
- ☐ Prescribed Physical Therapy
- ☒ Applying Heat or Cold
- ☐ Massage
- ☐ Assistive Devices (cane, shoe lift, brace...)
- ☐ Positioning
- ☐ Rest
- ☐ Joint Replacement Surgery (Total Hip, Total Knee, Birmingham Hip Resurfacing, Total Shoulder, Patella-Femoral Joint Arthroplasty, ...)
- ☐ Other treatment not listed here
- ☐ No Treatment

Next you will be asked to describe the results you experienced from the treatments that you selected. You will be asked if they decreased your pain or increased your pain. And then you will be asked if they increased or decreased your functioning (how your pain affected your ability to do the things you want to - walking, shopping, etc...)

<< BACK

NEXT >>

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Who wears the pa...pdf

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Please place a check mark next to your answers that describes the results you experienced from each treatment. (You can check more than one result for each of your answers.)

	Decreased my pain	Increased my pain	My symptoms did not change with this treatment
Exercise (biking, walking, swimming, or other)	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
NSAIDS: Ibuprofen - (Motrin, Advil), Naproxen - (Aleve), Aspirin - (Excedrin, Bufferin, Bayer)...	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Glucosamine	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Chondroitin	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Applying Heat or Cold	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please place a check mark next to your answers that describes the results you experienced from each treatment. (You can check more than one result for each of your answers.)

	Increased my functioning	Decreased my functioning	My symptoms did not change with this treatment
Exercise (biking, walking, swimming, or other)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NSAIDS: Ibuprofen - (Motrin, Advil), Naproxen - (Aleve), Aspirin - (Excedrin, Bufferin, Bayer)...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Glucosamine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please place a check mark next to your answers that describes the results you experienced from each treatment. (You can check more than one result for each of your answers.)

	Increased my functioning	Decreased my functioning	My symptoms did not change with this treatment
Exercise (biking, walking, swimming, or other)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NSAIDS: Ibuprofen - (Motrin, Advil), Naproxen - (Aleve), Aspirin - (Excedrin, Bufferin, Bayer)...	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Glucosamine	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Chondroitin	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Applying Heat or Cold	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

You have just described your first treatment plan from when you first began to treat your arthritis pain. If you need to add or delete any treatments you may use the back button and add to the list.

As a next step, please think about when you changed your treatment regimens (it may be helpful to think about events in your life to help you remember the year and month and when you changed regimens).

☒ OK, I'm ready to describe my next treatment regimen.
☐ This was my last time frame and reflects my current treatment regimen.

[<< BACK](#)
[NEXT >>](#)

OCTOBER STUDY LINK - x Online Survey Software - x The Leading Research 5 - x Gmail - Digital SLHC art: - x

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Apps Google Favorites HH Email HH Paycheck site UConn Library Qualtrics sign on HH portal

	Increased my functioning	Decreased my functioning	My symptoms did not change with this treatment
Exercise (biking, walking, swimming, or other)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NSAIDS (Ibuprofen - (Motrin, Advil), Naproxen - (Aleve), Aspirin - (Excedrin, Bufferin, Bayer)...	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Joint Replacement Surgery (Total Hip, Total Knee, Birmingham Hip Resurfacing, Total Shoulder, Patella-Femoral Joint Arthroplasty, ...)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

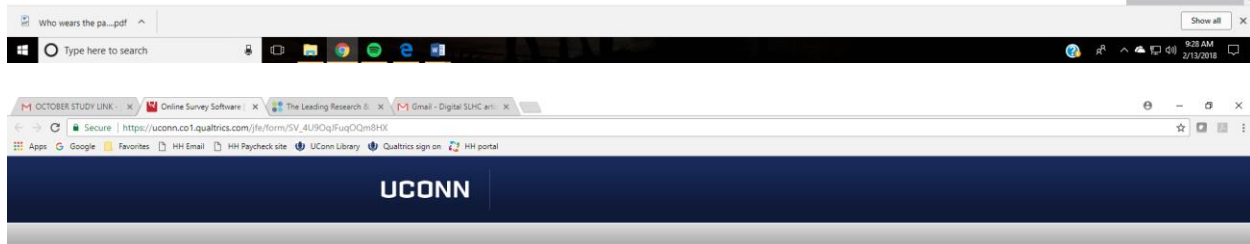
You have just described your second treatment plan from when you first began to treat your arthritis pain. If you need to add or delete any treatments you may use the back button and add to the list.

As a next step, please think about when you changed your treatment regimens (it may be helpful to think about events in your life to help you remember the year and month and when you changed regimens).

☐ OK, I'm ready to describe my next treatment regimen.
☒ This was my last time frame and reflects my current treatment regimen.

<< BACK NEXT >>

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You have finished!

Thank you for taking the time to fill out this Pain Management Life History Calendar. We believe that your participation will help researchers understand how people have treated their osteoarthritis pain over time.



Appendix G: Patient Focus Group Interview Guide

Introduction:

- Thank participants for their time and make introductions as appropriate
- Offer to discuss informed consent or answer any additional questions that anyone has regarding the study
- Housekeeping issues: where are bathrooms, refreshments (if any), when compensation will be paid (if there is any), session is expected to take approximately 90 minutes
- Distribute demographic forms, allow time to fill them in, and then collect them
- Direct participants to the computers provided and allow up to 30 minutes each to fill out their PMLHC. (Each participant will be given their PMLHC printout to keep).
- Review the purpose of the group (to generate conversations that highlights their opinions and ideas regarding the computerized pain management life history calendar (ePMLHC) that patients would fill out prior to office visits).

Group ground rules (will be posted on the wall)

- One speaker at a time.
- Please allow that there may be differences of opinion and be respectful of each other.
- You are encouraged to talk with and respond directly to each other
- All ideas are welcome (and encouraged).
- We are recording the session, but all names will be excluded from all reports so your comments are anonymous.
- Please put cell phones in quiet mode.

Questions

- Please think about the program you just used to fill in your PMLHC –
 - What are your first thoughts about the program?
 - What kind of challenges did you face while trying to fill out your PMLHC?
 - What did you like/ not like about using it?
 - What do you see as positive features?
 - What do you see as negative features?
 - Were the directions easy to understand?
- How do you imagine the printout could help you discuss your pain management with your provider?
 - What kinds of questions would you now have for your provider as a result of filling out this PMLHC?
- How do you feel about using computers to review and record your medical history?
- What additional questions should the computer ask to help guide your answers?
- Are there any additional suggestions you would like to make?

Follow up questions (to clarify discussion points and elicit more opinions from other members of the group as the discussion progresses).

- Summarize what has been said and ask if the group agrees
- Phrase questions in multiple ways
- Ask if there are others that want to comment on something just said (make brief eye contact with all members – especially if there are members who have not yet spoken)

Ask follow up questions

Appendix H: Older Adult Interview Guide

Introduction:

- Thank participant for their time and make introductions as appropriate
- Offer to discuss informed consent or answer any additional questions that anyone has regarding the study
- Housekeeping issues: where are bathrooms, refreshments (if any), when compensation will be paid (if there is any), session is expected to take approximately 60-90 minutes
- Distribute demographic forms, allow time to fill them in, and then collect them

Direct participant to the computer provided and allow up to 30 minutes to fill out their PMLHC.

Questions

- Please think about the program you just used to fill in your PMLHC –
 - What are your first thoughts about the program?
 - What kind of challenges did you face while trying to fill out your PMLHC?
 - What did you like/ not like about using it?
 - What do you see as positive features?
 - What do you see as negative features?
 - Were the directions easy to understand?
- How do you imagine the printout could help you discuss your pain management with your provider?
 - What kinds of questions would you now have for your provider as a result of filling out this PMLHC?
- How do you feel about using computers to review and record your medical history?
- What additional questions should the computer ask to help guide your answers?
- Are there any additional suggestions you would like to make?

Follow up questions (to clarify discussion points and elicit more opinions from other members of the group as the discussion progresses).

- Summarize what has been said and ask if the individual agrees
- Phrase questions in multiple ways
- Ask follow up questions

Modified Life History Calendar Interview:

- Starting from when your osteoarthritis pain began, tell me in the order of occurrence all that you did to treat your pain, including self-treatment, seeing a provider, using treatments prescribed by the provider, problems with the treatments, surgery, and anything else that you did to try to relieve your pain up to the present time.
- Please include the reasons for each of your actions.
- For each treatment, identify if your pain intensity decreased, increased, or remained unchanged and if your pain decreased, increased or did not affect your functioning.
- Additional neutrally worded questions will be used to elicit more detail as needed
 - Can you tell me more about that treatment?
 - What else do you remember about using that treatment?
- Ask follow up questions.